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HEARTNET



SOCIAL SUPPORT FOR SOUTH ASIAN CARDIAC PATIENTS



First Phase Report
Qualitative Interviews with 80 Cardiac Patients



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DEFINITION OF KEY TERMS



Ethnicity

The social group a person belongs to, and both identifies with and is identified with, as a result of a mix of cultural and other factors including language, diet, religion, ancestry, and race.

South Asian

Refers to a person whose ancestry is in the countries of the Indian sub-continent, including India, Pakistan, Bangladesh and Sri Lanka. This study will look specifically at people from a Pakistani background, since this specific community is more prevalent in the Whipps Cross area. The term 'south Asian' is generally used in this paper, since previous research has mainly focused on this wider group rather than Pakistanis in particular. References to this research use the term 'south Asian (Pakistani)' to underline the fact that this research will focus on this subgroup.

Social support

An exchange of resources between at least two individuals perceived by the provider or recipient to be intended to enhance the well-being of the recipient.

Social network

A person's social network may consist of spouse, parents, children, friends, neighbours, colleagues, co-workers, health care professionals, other shared interest groups, e.g. religious or social group memberships, etc. The quality of these networks are usually assessed by the individual's frequency of contact with them and physical proximity, etc. in the literature. Social network is one of the important dimensions of the social support construct. All studies regarding social support measure and report this dimension in order to describe major sources of support or relate it to other dimensions of social support.

Social support structure

Refers to the size, density and complexity of a person's family friends and other personal network members.

Functional social support

These refer to specific resources e.g. affection, feelings of belonging or material aid provided by members of a social network. These are:

Informational support is the process by which other people provide information advice and guidance

Tangible support consists of helping with home chores, providing transport etc. Positive social interaction is in terms of dinners, parties, movies, concerts etc.

Emotional support is in terms of approval and esteem given by another person, and a mutual provision of a 'climate of understanding'

Negative social support

Social exchange theory emphasises that social interaction imposes rewards and costs. The latter has generally been ignored in studies of social relations on psychological well-being.

Social integration index

Social Integration (SI) typically includes, marital status, close family and friends, participation in group activities, church and religious affiliations.

Natural social support

This refers to an individuals' pre-existing social network. This is in contrast to short-term constructed groups that may be developed for a specific intervention. Interventions aimed at restructuring naturally occurring networks and resources for support will be more effective than those that rely on short term constructed support groups (Berkman 1995).

Acute myocardial infarction

Defined by either unequivocal ECG evidence of a new MI with or without typical history, or a typical rise and fall in biochemical markers of myocardial damage, where the maximal value reached is greater than twice the upper limit of the hospital reference range, with either a typical history and/or new ECG changes indicating myocardial ischaemia

SOCIAL SUPPORT FOR CARDIAC PATIENTS - A FRAMEWORK



Introduction

Before dealing with the key findings from this research we will highlight the overall structure of the concepts referred to in this report and the relationships between key concepts. This structure also represents the way in which findings have been presented in the main body of the report.

The types of social support

- ≈ These are listed as emotional, tangible and information. These distinctions are drawn from the literature.
- ≈ In the reporting of the results these types of social support form the headings of the different sections of this report.

The context of social support

- ≈ These are the everyday mundane aspects that emotional, tangible and information social support takes.
- ≈ The specific contexts identified here have been generated from this research and have aspects are specific to cardiac patients.
- ≈ In the reporting of the results, these contexts form the major headings that are used in each section.

Support levels

- ≈ Deals with the idea that support can be provided at different levels, these can range from too little to too much. These parameters have been generated from this research.

- ❧ Other parameters by which social support can be judged are the extent to which it is subtle, whether it is provided on a perfunctory basis or out of emotional attachment. Another basis for measuring support can be the extent to which the person providing social support is undertaking any form of sacrifice and whether or not the social support actually has a negative effect.
- ❧ In the reporting of the results, for each type of social support we have covered issues related to dimensions after we deal with the different contexts.

Factors affecting support perception

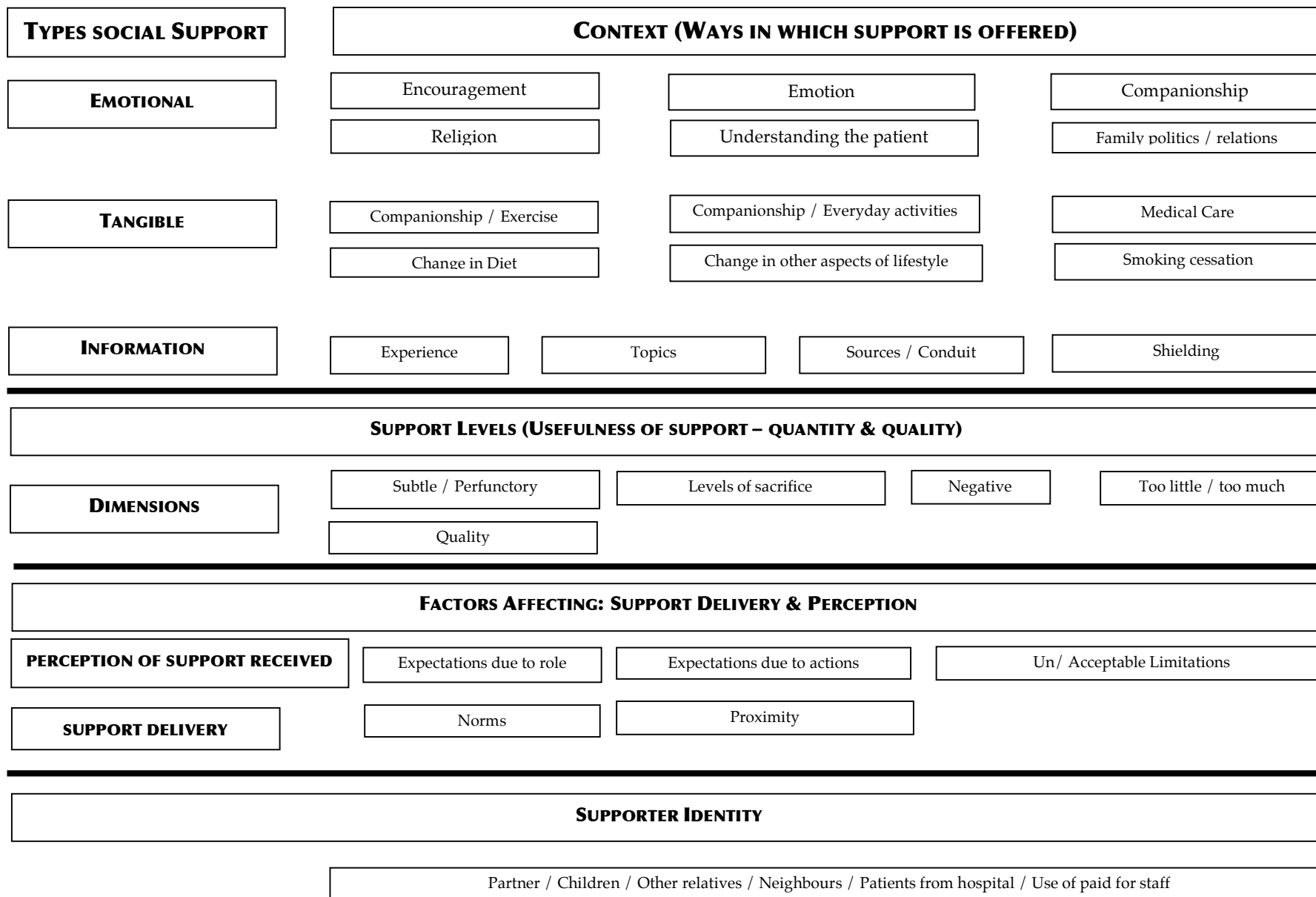
- ❧ These are identified as the expectations that patients can have in terms of their role within the wider family / social setting.
- ❧ We also identify expectations as being based on their previous dealings with family members and others.
- ❧ Patients cannot always be given the level of support they may need, this may be because social network members have limitations (for example due to age). As a result we also distinguish between limitations that the patient considers to be acceptable and those that are unacceptable.

Factors affecting support delivery

- ❧ We identify the following, social/ cultural norms and physical proximity.
- ❧ In terms of the structure of the report, issues to do with delivery and perception are considered after support levels.

Supporter identity

- ❧ Here we identify the different groups of individuals who can provide social support.
- ❧ These issues are considered at the end of each social support type.



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EXECUTIVE SUMMARY



Introduction

Here we identify the key findings for health promotion. The findings are presented in terms of the key types of social support that we have studied in this research namely, emotional, tangible and information support.

Overall this research has found the following:

- ❧ South Asian patients experience heart disease in a **social context** that includes not only the spouse but also children and other family members
- ❧ South Asian patients have to **socially negotiate** their heart disease with a wider social network that may not understand the implications of having heart disease
- ❧ The South Asian patients' **social networks** can be a source of information, emotional support and tangible resources however they can also prove to have **liabilities in terms of social norms, expectations and conventions**. For the South Asian patient, living with heart disease can involve trying to benefit from the resources available while dealing with the liabilities
- ❧ Some South Asian patients may still have strong ties with friends and relatives in the Indian sub-continent as a result they may be exposed to the information and beliefs about heart disease prevalent there. Some of these may be inaccurate.
- ❧ Some Asians may not always have the social network resources (e.g. help from close relatives) that they would normally be expected to have. In these instances they may need to develop resource networks with neighbours and other patients (often from outside their racial/religious community).

Key Findings for health promotion

- ☞ Overall the findings are that with South Asian cardiac patients family members can play a significant and pro-active role in helping to manage their health. Such help ranges from transport arrangements, to diet and medication.
 - ☞ However, there are clear instances of British Asian cardiac patients receiving dubious information and advice from members of their social networks. Given the impact of the opinions of family relatives on cardiac patients, there are therefore, implications for health promotion. Campaigns could address common misconceptions – for example the efficacy of traditional Asian remedies as an alternative to modern treatments.
- ☞ In addition given the number and extent of close relationships that Asians may have, there is also the issue of intra-family politics that may affect the stress levels of patients.
 - ☞ If the Asian community more widely were made aware of the negative impact of such stress this could be quite important. Moreover relatives' attention could also be brought to one of the findings from this study that a cardiac event can also bring estranged relatives together.

Finally this study provides a host of practical ideas of the ways in which patients and their relatives can use social relations as a means of helping to manage cardiac health – these are considered below.

Tangible Support

- ☞ The extent to which family members helped patients move to a healthier diet ranged from making no changes at all to changing the diet for the whole family.
 - ☞ Health promotion campaigns could emphasise the benefits of the latter level of change.
 - ☞ Moreover where this is not possible they could point out the less drastic changes that can be made – for example taking out a portion of food for the cardiac patient, before oil is added to the portions for everyone else, for example.
 - ☞ This can be important in Asian households where families may be characterised by relatively high susceptibility to heart disease.
- ☞ Most Asian respondents referred to being taken to hospital in the event of angina pain / MI by a family relative.
 - ☞ This may be due to social and cultural norms, with family members expected to take a proactive role in a crisis.
 - ☞ The health promotion implication is that it may help to have Asians generally made aware of what should be done in such an event – specifically the benefits of calling an ambulance.
- ☞ Traditionally, Asians may expect to use close friends and relations for help with such activities as exercise. However we found instances where this was not possible and some Asians were resorting to developing friends and exercise buddies beyond the traditional networks.
 - ☞ The implication is that the BHF may need to make patients aware that they can develop social relationships, with other patients (outside the immediate social network) for the purposes of exercise and exchanging information and these can be particularly valuable where they do not have access to existing relationships.
- ☞ A number of patients (South Asian and indigenous British) talked in positive terms about the benefits of doing things together with their spouses. But the South Asians also referred to such activities with other close relatives.

- ☞ Such activities can include cooking and taking exercise. It is interesting to note that Asian respondents talked about not just companionship from the spouse, but also other close relatives such as sons and daughters-in-law.
 - ☞ The implication for health promotion is that any literature which deals with rehabilitation may need to take into account that patients may well involve people other than spouses.
- ☞ **Although South Asians may generally be regarded as getting help from members of their social networks, this is not always the case and some patients referred to the help they received as falling short of their expectations.**
 - ☞ South Asians may need to be made aware of institutional sources of help, which they may not ordinarily be aware of.
- ☞ **Patients referred to receiving levels of care that ranged from 'too little' to 'too much'.**
 - ☞ Health promotion literature may need to inform Asians generally (i.e. not just patients) about the different levels of care that they can give and the fact that although social and cultural norms may require them to offer certain levels of care, these may be inappropriate.
- ☞ **Negotiating social conventions**
 - ☞ Dealing with other peoples' expectations and social conventions can be important, even if one is a cardiac patient. Some patients referred to the methods they used in order to negotiate their way through such conventions in order to maintain a healthy lifestyle. For example some patients eat before going to relatives when they know that the food to be served will not take into account their dietary requirements – this allows them to eat much less than they otherwise would. Others commented that outright refusal to eat can offend, so they make a show of eating.
 - ☞ Patients' better knowledge of dietary restrictions can mean that there are a greater possible range of instances where they have to ask friends and relatives to serve healthy food. Where this is not done, there is scope for the patient to perceive that their health is not being given due attention. **The implication is that the community more generally needs to be made aware of the dietary requirements of people with heart disease.**

Emotional Support

- ☞ **One of the forms taken by emotional support is 'showing understanding'.**
 - ☞ However social network members of patients, because of social and cultural norms may not show such understanding. For example, social conventions may require people to visit hospital and this may mean that many relatives appear at once, at the very least causing embarrassment to the patient. Health promotion literature aimed at the Asian community in general may need to stress the importance of 'showing understanding'.
- ☞ **Impact of the cardiac event on family politics and relations.**
 - ☞ For many respondents the cardiac event proved to be a turning point in their relations with others (often for the better). This is an issue that could be more widely known, so that people can know how this situation can be used to improve relations and reduce stress.
- ☞ **Worrying about other people**
 - ☞ A recurring theme in respondents' feedback was that they realised that they should worry less about family and relations. Since this could be a cause for stress, Asian patients could be asked to consider this if they feel there is a lot of stress in their lives.

Information Support

☞ Relatives may use information sources that the patient does not

- ☞ This highlights the importance of talking about cardiac issues and exchanging information with others. This may mean that any health promotion campaigns may need to be directed at the community level and not just at patients.

☞ Spouse may be a conduit for information from others

- ☞ Health promotion literature may need to make spouses aware of this possible role and its usefulness to the cardiac patient.

☞ Information quality depends on source

- ☞ Many patients recognised that the information that they received from certain sources was not reliable and as a result they discounted it. However the possibility remains that patients are influenced by such information and health promotion may need to highlight that patients should be careful as to the information that they take on board regarding heart disease and their treatment.

☞ Patient as a source of information to others.

- ☞ Sharing experiences and information obtained from reliable sources can be very useful for others and patients could be encouraged to do this.

☞ Asian respondents referred to family members helping with medication

- ☞ The broader Asian community may need to be better informed about medications for cardiac patients and the negative aspects of unorthodox treatments. They may also need to be informed about the issues surrounding the use of medical treatment overseas

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IMPLICATIONS FOR HEARTNET STAGE II



Introduction

This research represents the first stage of the HEARTNET project. The second stage is anticipated to be a social marketing exercise that makes use of the social support paradigm. Based on the findings from this research we would propose the aims and objectives of such an exercise to be as follows:

Aim

The aim of Phase II would be to:

- ≈ communicate to South Asians the advantages and limitations of social support and how it can be effectively leveraged

Objectives

The objectives of such a campaign would be to:

- ≈ show South Asian cardiac patients how they can leverage the resources provided by their social network members
- ≈ highlight to both cardiac patients and those who may be part of their social networks the possible limitations of social networks and the negative aspects of social support

Communication strategies

The ways in which we will achieve those objectives would be as follows:

- ☞ Discussion programmes on Asian radio and TV where we would discuss the ways in which people have positively made use of social networks and also where social networks have proven to be a liability.
- ☞ Newspaper & magazine articles that highlight the findings from this research and present it in the form of real life patients' experiences.
- ☞ A website containing information in English and a number of different Asian languages about heart disease and the possible role of a cardiac patient's social network members. Such information would be targeted at not just patients, but South Asians more generally. References to the website URL, as a source of further information, would be given in any press coverage.
- ☞ Booklets made available for relatives and friends of cardiac patients which deal with their role in helping patients maintain healthy lifestyles.
- ☞ A presence at Melas that would enable us to reach the community directly.

Anticipated outcomes

We would expect to see the following measurable outcomes as a result of this campaign:

- ☞ Improved levels of knowledge about heart disease, specifically related to dietary and other lifestyle issues in the South Asian community.
- ☞ Specific improvements in people's understanding of the social relevance of managing heart disease e.g. the role of family and friends in providing a social environment that helps cardiac patients maintain a healthy lifestyle.

IMPLICATIONS FOR RESEARCH



These findings provide a rich basis for subsequent quantitative research. We have identified some key constructs that are relevant for understanding social support in a South Asian context. We can now identify existing measures in the literature that could help to measure the extent of social support. Moreover such a tool can also be used in order to assess the before and after effects of any social marketing intervention.

For example we can measure the extent of emotional, tangible and information support received by patients and we can adapt any existing measures in the literature to the specific issues identified in this research. We can also measure the extent to which support is offered and also issues to do with perception. Finally we can also try and measure the extent to which support is received from different sources.

The measures that are developed based on the findings from this research could also be used to measure inter-ethnic differences and within the same ethnic groups – but varying by geographic domicile.

There were a number of important findings, which may have limited impact on a social, marketing campaign but which could be the focus of further research. There were clear links between the different types of support. The nature of these linkages and their impact on patients could be investigated further.

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BACKGROUND



HeartNet as originally designed to deliver orthodox cardiac rehabilitation advice (e.g. regarding exercise and diet) using the novel medium of patients' social networks. Following an extensive literature review it became clear that the focus of existing research had been on the related field of social support. However existing research had not dealt with the meaning of social support within a south Asian cultural context, specifically one where cardiac health was concerned.

Further qualitative research in the above area led us to identify some important issues concerning the ways in which south Asian cardiac patients manage their health and negotiate the lifestyle changes that they have to make within cultural norms and requirements. We also found evidence of the ways in which social network members (friends and family) respond to cardiac patients and the ways in which the behaviour of those friends and family is construed in either a positive or negative light by cardiac patients.

Based on those findings from the literature review, the nature of the project was amended. We decided to initially investigate the meaning of social support within a South Asian context and then assess the significance of the findings before proceeding with a social marketing campaign.

In summary what we have found is rich qualitative evidence of the everyday social management of heart disease by South Asian cardiac patients and this could inform any health promotion campaign aimed at this particular group of people.

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INTRODUCTION



Introduction

People of South Asian origin (people with ancestry from India, Pakistan, Bangladesh and Sri Lanka), have a higher propensity to CHD than the UK population in general (Wild & McKeigue 1997). Furthermore there are also evidences suggesting a higher prevalence of cardiac risk factors (such as insulin resistance, diabetes and high cholesterol) and cardiac risk prone behaviours (such as, obesity, low physical activity, smoking and high fat diet) among this population^{12,13}. The lower levels of knowledge and understanding of CHD risk factors in these communities compound this problem (Datta 1995). There is also a lower level of uptake of services within these communities (Mc Keigh & Miller 1998) and compliance with drugs regimes. In particular research shows that the first generation of immigrants have higher levels of mortality attributed to heart disease than other population groups (Balarajan 1996).

Given the problems faced by this minority ethnic group, the purpose of this research has been to gather insights into the way in which social support is provided by friends and relatives to cardiac patients of South Asian origin. In particular we have focused on South Asians of Urdu speaking origin, who are originally from Pakistan. For this research we have also gathered data from other ethnic groups in order to throw into sharper relief how Asian cultural norms may have changed or adapted to the British context.

Shumaker and Brownell (1984:31) define social support as 'an exchange of resources between at least two individuals perceived by the provider or recipient to be intended to enhance the well-being of the recipient'. Its function is to give information to an individual that he/she is loved, cared for, esteemed, valued and belongs to a mutually obliging communication network.

Over the past 30 years been a number of different types of studies dealing with social support and specifically social support for cardiovascular disease patients. While a number of important insights have been gained, important gaps in knowledge remain. Specifically the meaning of social support in a South Asian community has not been investigated nor indeed have existing measures of social support been applied in that context. This paper will set the background for a study that involves an in-depth examination of what social support actually means in a South Asian context as well as the development of a scale measuring social support that is appropriate for use within that community.

The structure of this paper is as follows. We start with an overall conceptual explanation of social support. The next section of the paper deals with the relevance of social support to cardiovascular disease. The context of this research is the development of culturally appropriate social support for a south Asian community. In order to focus on this issue we deal in turn with some literature dealing with social support within minority communities and the role of negative social support, we also consider the possible role of additional constructs that could be relevant to understanding social support within a south Asian community.

Anderson et al (1996) argue that social support is important for recovery from and adaptation to chronic disease such as cardiovascular disease (CVD) and it is equally important for the primary and secondary prevention of myocardial infarction (MI). Furthermore they say that 'deficient social support is a risk factor for morbidity, mortality from CVD and MI and for poorer rehabilitation and lower compliance to rehabilitation programmes'. Post MI patients who suffer from a lack of social support should be identified. Assessment of levels of social support can be undertaken using measures identified in the literature. The measures have been associated with psychosocial well-being and are clinically very important for rehabilitation.

Cardiovascular disease and social support

Social support is supposed to be protective of cardiovascular health. This is supported in cross-sectional and longitudinal population studies, in intervention studies with humans and animal experiments (Kristina Orth-Gomer 1994). In multivariate analyses controlling for standard risk factors (blood pressure, lipids, coagulation factors, family history, sedentary lifestyle, etc.) two factors emerged as the strongest independent risk factors for MI in middle aged men: smoking and lack of social support (Orth-Gomer, Rosengren and Wilhelmsen 1993). This was the first study to prospectively link social support to the occurrence of heart disease.

Frequency of social contacts, the number of available persons and the amount of social activities seem to have a substantial effect on health and survival. If size and density of social networks have an effect on health this could be due to qualitative rather than quantitative characteristics of the social interaction. Also social interaction if improper could be a stressful

factor in itself and may promote rather than inhibit illness. Recent studies have sought to develop qualitative measures that could tap into those aspects (Orth-Gomer & Undén A-L 1987). Stansfeld (1999) argues that a richness of analysis may be obtained by examining the quality of support as well as the social network.

Social support within minority communities

Hazuda examined ethnic differences in social support-cardiovascular disease relationship and suggested that the meaning of bonds and social isolation in a highly cohesive group as Japanese Americans may differ from groups that are less cohesive. They proposed that the greater the cohesion of a social group the greater the effect of isolation on health. Race was not associated with either CAD or network characteristics in a pooled sample of whites and non-whites (Seeman 1984), this suggests that ethnic and racial variation in the association between social support and CAD is negligible (Kristina Orth-Gomer 1994).

The meaning of social ties for particular individuals or subgroups varies according to the social context in which people carry out their day-to-day activities. Ethnic variation may be a special case of social context effects; thus, the meaning of ties and strength of their association with IHD mortality may vary across population subgroups as a function of their ethnic make-up (Orth-Gomer 1994).

Bradhead, Kaplan and James (1983) noted that the benefits of social support might increase with decreasing socioeconomic status. Compared to more affluent and better-educated individuals, members of families of low socioeconomic status are probably more dependent on their informal social networks for the provision of essential goods and services...well functioning social networks assume even greater importance for the health of this group. Ethnographic studies of black communities have documented the crucial role of the extended family as a unique and important source of resources and support in the face of adversity. This suggests that studying social support could be particularly relevant where the focus of attention is South Asians, particularly those living in a relatively deprived area of London.

Negative social support

Social exchange theory emphasises that social interaction imposes rewards and costs. The latter has generally been ignored in studies of social relations on psychological well-being. There is a tendency to equate social interaction with social support – however it can be important to distinguish positive and negative social outcomes and examine their relative effects on psychological well being (Rook 1984).

It is commonly held that frequent interaction with friends and relatives is equated with high level of social support. However such interaction can involve costs as well, for example, disputes, embarrassment, envy, and invasion of privacy. Social relations are usually studied in terms of their buffering effect i.e. improving the ability of people to cope with stressful

situations. The reverse hypothesis that such relations could lead to stressful events and make symptoms worse has been investigated far less (Rook 1984).

Social exchange theory suggests that people will construct social ties on the basis of their capacity to provide rewards relative to costs and as a function of the alternatives available. Choice should lead people to construct social networks composed mainly of rewarding ties. However there can be constraints that limit an individual's choice of those with whom interaction takes place. Some contacts may be unwanted and aversive in nature. Also negative experiences of contacts, even if they are infrequent may have greater impact because they are rarer and more salient. Negative social experiences with others may detract from well-being to a greater extent than positive experiences enhance well-being (Rook 1984).

Results presented in Uchino et al (2001) show that social network ambivalence was a relatively unique predictor of cardiovascular reactivity and highlights the utility of separating the variance due to positive, negative and ambivalent network ties. Ambivalent network members are described as being sources of both positivity and negativity and these can be associated with increased psychological distress.

Constructs relevant to south Asians

One of the reasons why we have undertaken qualitative, depth interviews with South Asian cardiac patients is because of the possible existence of culturally relevant constructs in social support in a South Asian context, which have not been a feature of existing measures of social support.

A review of some of the culture literature in the field of health shows that researchers have found constructs that are relevant when dealing with Pakistani/Muslim/elderly patients that we can identify as being related to social support. This suggests that not only may these constructs be identified in a qualitative study, but also that there may be more constructs that should be considered. We deal with three such constructs here, 'hospitality', 'filial piety' and 'respect'.

Bush et al (1998) draw attention to family hospitality and ethnic tradition in South Asian families. They cite Bush et al (1995) and say that South Asian heart disease in Britain has been linked to central fat deposition and studies have also shown high waist and waist/hip measures, and the measures have been higher amongst those who have been long resident in the UK. The authors consider a number of factors that include, 'the extent to which food sharing and food exchange follow obligatory patterns of high energy intake in which health is not a major consideration' Bush et al (1998:2).

This is an important construct in our estimation because 'hospitality' is by its very nature social, it exists when the patient interacts with members of their social environment. Furthermore hospitality that involves the serving of fatty/high energy food will have a direct impact on the health of a cardiac patient. In terms of our study positive social support would

exist where members of the social network are able to provide the patient with low fat/calorie alternatives and negative social support would exist where hospitality only involves the serving of traditional foods.

The second construct that we consider relevant is 'filial piety'. Gatrad et al (2002) identified this issue when dealing with palliative care for Muslims. This notion refers to 'unconditional loyalty, respect, love and honour' for the elders in the family. The authors note however that such care is eroding as more professional Muslims move away from family homes. Thus this may be an aspect of social support that Asian cardiac patients expect, but do not receive and as a result its absence may have a negative impact on Asian patients that would not occur for white patients, who may not perceive the absence of filial piety.

Finally, Clegg (2003) in a study dealing with older South Asian patients and carer perceptions of culturally sensitive care explains the role of 'respect'. Clegg says that there are differences in the way in which different cultures demonstrate their respect for another human being. The degree of deference displayed in behaviours and body language, varies depending on social and cultural norms. An older asian woman felt that she had retained her status within the family as an older asian woman, and felt that she received more respect at home than in the wider community. Where people feel discriminated against they derive their self-esteem from their position among fellow Pakistanis (Blakemore and Boneham 1994) cited by Clegg (2003). Respect would be distinct from filial piety since the former would be expected from friends and relations whereas filial piety would only be expected from children.

Functional content and quality of social relationships

The functional content of social relationships in terms of social support has been conceptualised as four types of support in literature: emotional, instrumental, informational and appraisal.

House and Kahn (House and Kahn 1985) argue that priority should be given to measuring emotional support, as this has been most clearly linked to health, in terms of both direct effects and buffering effects. Positive emotional support was also found to be protective against cardiovascular disease (Orth-Gomér 1994).

Instrumental support refers to the availability and or actual utilisation of practical help, such as running errands, cooking meals, etc. from the individual's social network members. This dimension of social support is particularly relevant for older individuals with non-psychiatric conditions (van den Akker-Scheek et al. 2004). Both emotional and instrumental support measures are usually included in studies looking at the relationship between social support and cardiovascular disease (Orth-Gomér 1994).

Informational support refers to advice while appraisal support refers to evaluative feedback (Tardy 1985).

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MEASUREMENT OF SOCIAL SUPPORT

The design of the data collection instrument to be used in the second phase of the project will be finalised once we have analysed data from the first (qualitative) phase of the project.

However, the following text explains which measures we currently anticipate using at the second phase.

Measuring social support

According to House and Kahn (1985, p.85), “It is desirable on both substantive and methodological grounds that at least two, and preferably all three, of these aspects of social relationships be explicitly conceptualised and measured within a single study”. Following their advice, we will incorporate all three dimensions of network size, social interaction, and the functional content of social support in the proposed study. In addition, we will include the dimensions of perceived helpfulness and the negative aspect of social relationships. Details of these dimensions and scale selection are discussed below.

There is substantial empirical evidence showing the effect of the existence and quantity of social relationships, e.g. marriage, friendship, community relations, on health outcomes (House and Kahn 1985). House and Kahn suggest that the assessment of social relationships should be a standard part of studies of social support. In particular, the marital status, number and frequency of contact with friends and relatives, and participation in community and voluntary organisations are important. In our proposed study, information on marital status will be collected as part of demographic data. Specific questions regarding the existence and frequency of social contacts are contained in the ‘social interaction subscale’ of the Duke Social Support Index (DSSI), which we will utilise in the present study as explained later in this section.

Most social support studies include measures of social network analysis in order to assess the structure of social relationships. Although the term 'network' is used frequently among these researchers, the actual definition and assessment methods vary greatly across studies.

Network size, density, i.e. the extent to which members of a network are linked to each other, and reciprocity are the most frequently and uniformly studied variables (House and Kahn 1985; Tardy 1985). Carrying out a thorough network analysis is costly, and the advantages of doing that have not been empirically proven. Hence, House and Kahn suggest being selective in measuring network properties, and perhaps focus on the ones that have been shown to be important, such as density, reciprocity and sex composition. The authors also point out that network analyses have often proved most informative when they focused on the content and quality as well as the structure of relationships.

After reviewing different measures of social support, Tardy (1985) concludes that there are mainly two different strategies for assessing social networks. The first one is to ask the respondents to supply the names and descriptions of people in their social networks, e.g. Barrera (1981), McFarlane et al. (1981). The other procedure involves specifying certain possible relationships, e.g. spouse, family, friends, and asking respondents to describe or evaluate the support they get from those individuals, e.g. Procidano and Heller (1983). Tardy suggests that both procedures are acceptable, and that researchers may choose between the two procedures, or even combine them. Based on this observation, we will combine these two methods. First, we will use McFarlane et al.'s scale, where the supporters are listed individually by the respondent, indicating their relationship, and assessing the perceived helpfulness and the possible negative aspect of the relationship. We will also incorporate the 'social network subscale' and the 'social interaction subscale' from the well-known Duke Social Support Index (Landerman et al. 1989), where the respondents give details of the network size and their interactions with network members as listed in the instrument. The DSSI embodies the multidimensional nature of the social support construct by incorporating four major dimensions of social support, namely, social network, social interaction, emotional support and instrumental support. It is a scale frequently used in literature, with good levels of reliability and validity (Koenig et al. 1993, ;van den Akker-Scheek et al. 2004).

Functional content and quality of social relationships

The functional content of social relationships in terms of social support has been conceptualised as four types of support in literature: emotional, instrumental, informational and appraisal.

House and Kahn (House and Kahn 1985) argue that priority should be given to measuring emotional support, as this has been most clearly linked to health, in terms of both direct effects and buffering effects. Positive emotional support was also found to be protective against cardiovascular disease (Orth-Gomér 1994).

Instrumental support refers to the availability and or actual utilisation of practical help, such as running errands, cooking meals, etc. from the individual's social network members. This

dimension of social support is particularly relevant for older individuals with non-psychiatric conditions (van den Akker-Scheek et al. 2004). Both emotional and instrumental support measures are usually included in studies looking at the relationship between social support and cardiovascular disease (Orth-Gomér 1994). Hence, we will include these two dimensions by using the DSSI. Similar to van den Akker-Scheek et al. (2004), we will delete the item related to childcare, as it is not relevant to elderly cardiac patients. Following van den Akker-Scheek et al.'s (2004) methodology, we will construct the DSSI subscales as 4-point Likert type scales with four possible responses: (1) never or rarely, (2) now and then, (3) regularly and (4) often. We will also assess concurrent validity using the Social Support List 12-Interactions (SSL12-I) scale. This instrument will be incorporated into our questionnaires sent to research participants, with half of respondents completing it before our instrument and the other half afterwards. The SSL12-I was shown to be a reliable and valid instrument developed to measure social support in older people (Kempen and Van Eijk 1995).

Informational support refers to advice while appraisal support refers to evaluative feedback (Tardy 1985). Due to practical considerations about questionnaire length, these two subdimensions of the functional content of social support will not be included in our proposed study.

Perceived helpfulness of social relationships and social support

A distinction is made in literature about the objective versus subjective assessments of social relationships and support. Some researchers pointed out that some of the functional contents of social support might be more subjective (e.g. emotional and appraisal) than others (e.g. instrumental). Other researchers included separate perception-based measures in their studies. McFarlane et al.'s (1981) 'Social Relationship Scale' (SRS) is frequently mentioned in the literature as an example of a subjective scale assessing the perceived helpfulness of available social relationships with a person's social network members (House and Kahn 1985; Tardy 1985; Orth-Gomér and Undén 1987). SRS inherently assesses the negative side of these relationships as the 'helpfulness of discussion' with each network member can be marked on a 7-point Likert-type scale ranging from 'make things a lot worse' to 'help things a lot'. The scale also includes the 'reciprocity' dimension of social support. The authors established the reliability and validity of this scale by providing evidence for content validity, criterion validity, test-retest reliability and response bias. Tardy (1985) points out that the psychometric evidence warrants continued use of this measure; and that the provision for assessing negative outcomes of social support as well as positive ones is an added advantage. Hence, we propose to include McFarlane et al.'s scale to assess each respondent's social network and the perceived helpfulness from the individuals in the network with specific regard to the respondent's health condition. However, Tardy also warns that, due to the wording of the scale, the items may result in individuals being listed just because they converse with the respondent rather than give any support. Therefore, we will change the wording on the scale from "I discuss my health condition with:..." to "I get help/support regarding my health condition from:...".

Control variables

In addition to the measures related to social support and culture-specific constructs, we will aim to include some control measures in the quantitative survey phase of the study. First, demographic data on age, gender, marital status, education and employment status will be collected. Ethnic background data is also needed, as this study explicitly aims to compare two different ethnic groups, i.e. south Asian versus Caucasian. Certain psychological variables, such as mood, anxiety and depression, (locus of control?) will also be included, as respondents' self-reported measures of social support may be a function of how they feel at the time of completing the instrument (Tardy 1985). Similar to other cardiovascular disease context-specific studies of social support, medical data, such as blood pressure, will also be collected for statistical control purposes.

9

RESEARCH QUESTION METHODOLOGY & SAMPLE DESCRIPTION



Introduction

This was a qualitative piece of research whose aim was to find out about social support for a South Asian group of patients. While there has been extensive previous research on social support this has not been the case with this particular group.

In this section we will deal with the method used to gather the data and pay special attention to describing the sample.

An important aspect of the methodology was the development of the interview protocol and this will be discussed in the next section.

Research Question

The question driving this research was:

❧ What is does social support mean to South Asian cardiac patients?

As the literature review has shown there has been extensive research into social support for cardiac patients in a number of different settings. However what remains unexplored is the meaning of social support for this particular group of people.

Given the way in which social support may be grounded within interpersonal relations amongst a range of people (in addition to the partner or spouse) it is quite important that for

Asian patients we consider the nature of social support beyond the notion of the dyadic relationship between husband and wife. This distinguishes our research from a lot of existing social support literature since that deals primarily with husband and wife relations.

In addition to the main research question, we also had the following subsidiary questions.

- ❧ What are the differences between social support for South Asian patients and indigenous Britons?

The reason for asking this question was to assess whether there was, in fact, any reason to deal with social support for South Asians in a different manner to indigenous Britons. In addition the question would help to throw into relief significant aspects of South Asian specific issues.

- ❧ What are the differences between South Asians of Pakistani origin and other South Asian groups?

This question was asked in order to assess whether a health promotion programme aimed at South Asians of Pakistani origins would need to be any different to one aimed at South Asians more generally.

- ❧ What are the differences between British Pakistani's and those resident in Pakistan

We wanted to ask this question in order to explore more deeply issues to do with culture and how these varied between people who otherwise spoke the same language, and shared the same religion.

Associated with each additional question was a specific group of respondents. In order to compare and contrast findings with the indigenous British respondents we interviewed 20 indigenous British respondents, we also interviewed 20 Pakistan based respondents, and 10 British Asians.

It should be noted that apart from the main research question the others are being asked in order to throw into relief the findings from the main British-Pakistani cohort of respondents.

Methodology

In this section we will deal with the aspects of methodology dealing with sample selection. Overall there were 4 different samples selected:

- a) The main cohort of 20 Urdu speaking Pakistanis based in the UK
- b) A comparative sample of 20 indigenous Britons based in the UK
- c) A comparative sample of 20 Urdu speaking Pakistanis living in Pakistan
- d) A comparative sample 10 non Pakistanis living in the UK
- e) A final sample of 10 Urdu speaking Pakistanis based in the UK – this group was used to clarify issues that had arisen over the course of the previous interviews.

Altogether 80 respondents were interviewed.

Sample selection and description

Respondents were acquired principally on a convenience basis with respondents being asked to recommend any other members of their social networks. Payments were not made for the interviews.

Each interview typically lasted for 40 minutes and depending on the patients' permission they were taped. Interviews followed the protocols discussed in the next section, except where the patient discussed an issue that had not been anticipated and this was probed further.

Two medically qualified doctors who had experience in the field of cardiology undertook the interviews. The two doctors were trained in the interview protocol by one of the researchers for this project.

Given the grounded nature of this project there were no systematic attempts made to control the sample in terms of age, previous occupation, gender etc. Given the impact of working on social relationships we deliberately avoided people who were working and focused on those who had retired.

Overall as can be seen the Pakistani respondents tended to be relatively younger than their indigenous British counterparts – but that mirrors the experience of heart disease in the UK, where the incidence of heart disease amongst south Asians.

The main cohort (20 respondents)

Interview ID	Age	Gender	Marital Status	Children	Other
UK PK 1	>60yrs	Male	Married	4	(Khaliq Mamoo)
UK PK 2	>60yrs	Male	Married	Yes	
UK PK 3	>60yrs	Female	Married	1	(Firdous Anty)
UK PK 4	66yrs	Male	Married	2	
UK PK 5	65yrs	Male	Married	2	Zia-Ur-Rehman
UK PK 6	62yrs	Male	Married	3	
UK PK 7	60yrs	Female	Married	3	Bangladeshi Origin
UK PK 8	63yrs	Male	Married	1	
UK PK 9	>60yrs	Male	Married	2	
UK PK 10	64yrs	Female	Married	2	
UK PK 11	64yrs	Male	Married	1	
UK PK 12	66yrs	Male	Married	2+	
UK PK 13	>65yrs	Male	Widower	Yes	
UK PK 14	69yrs	Male	Widower	1	
UK PK 15	60yrs	Male	Married	1	
UK PK 16	>70yrs	Male	Married	2	
UK PK 17	62yrs	Male	Married	2+	
UK PK 18	60yrs	Female	Widow	1	
UK PK 19	>70yrs	Male	Married	1	Firdous Antie's Husband
UK PK 20	73yrs	Female	Married	2	Patients sister live with her.

A comparative UK indigenous sample (20 respondents)

Interview ID	Age	Gender	Marital Status	Children	Other
UK Eng 1	60yrs	Female	Married	1	Swan Alma
UK Eng 2	72yrs	Female	Divorced	17	Married Thrice
UK Eng 3	61yrs	Female	Widow	2	Widow
UK Eng 4	63yrs	Female	Married	2	
UK Eng 5	62yrs	Male	Married	3	Buggy Richards
UK Eng 6	70yrs	Male	Married	2	
UK Eng 7	60yrs	Male	Married	4	2 Children of Patient & 2 children of Patients 2 nd Wife
UK Eng 8	>60yrs	Male	Married	1	
UK Eng 9	71yrs	Male	Married	2	2 Duaghters
UK Eng 10	91yrs	Male	Widower	1	1 Daughter
UK Eng 11	61yrs	Male	Married	5	1 leg amputated
UK Eng 12	>60yrs	Male	Widower	1	
UK Eng 13	66yrs	Male	Married	Nil	John Nolar
UK Eng 14	86yrs	Male	Married	Nil	Ridgway Eric
UK Eng 15	60yrs	Female	Married	2	
UK Eng 16	72yrs	Male	Married	2+	
UK Eng 17	>65yrs	Female	Married	2	Husband Doesn't live with the Patient
UK Eng 18	>60yrs	Male	Married	3	
UK Eng 19	86yrs	Female	Widow	1	Roberts Ethel
UK Eng 20	87yrs	Female	Widowed	Yes	Fitton Freda

A comparative Pakistani indigenous sample (20 respondents)

Interview ID	Age	Gender	Marital Status	Children	Other
PK PK 1	64yrs	Male	Married	5	Syed Abdul Waheed
PK PK 2	72yrs	Female	Married	4	Zubaida Ikram
PK PK 3	68yrs	Male	Married	1	Noor-E-Nazar
PK PK 4	63yrs	Female	Married	9	Mrs Nasir
PK PK 5	62yrs	Male	Married	2	
PK PK 6	61yrs	Male	Unmarried	Nil	Qasim Abbas
PK PK 7	>60yrs	Female	Married	2	Amna Bibi
PK PK 8	74yrs	Female	Married	6	Tanzeer Fatima
PK PK 9	61yrs	Female	Married	3	Gulzar Fatima
PK PK 10	>60yrs	Male	Married	2+	
PK PK 11	60yrs	Female	Married	Nil	
PK PK 12	63yrs	Male	Married	1	Nayab khan
PK PK 13	68yrs	Male	Married	3	Nisar Ahmed
PK PK 14	60yrs	Female	Married	1	
PK PK 15	62yrs	Female	Married	2	
PK PK 16	60yrs	Female	Married	3	Sarfaraz-Un-Nisa
PK PK 17	62yrs	Male	Married	4	Agha Liaquat Hussain
PK PK 18	65yrs	Male	Married	1	
PK PK 19	>60yrs	Male	Unmarried	Nil	
PK PK 20	>60yrs	Female	Married	1+	

A comparative UK Asian sample (10 respondents)

Interview ID	Age	Gender	Marital Status	Children	Other
Asian 1	67yrs	Male	Married	1	Ali Akrom
Asian 2	66yrs	Male	Married	2	Ajay Teripathi
Asian 3	64yrs	Male	Married	2	Khalid Masood
Asian 4	64yrs	Male	Widower	2	Harinder Singh
Asian 5	61yrs	Female	Married	2	Nazli Nasar
Asian 6	67yrs	Male	Married	2 Daughters	Mozaffar Ahamed
Asian 7	64yrs	Male	Married	3+	Anil Mehta
Asian 8	60yrs	Females	Married	2 Daughters, 1 Son	Nasreen Reza
Asian 9	68yrs	Male	Married	2+	Rahul
Asian 10	68yrs	Male	Married	1+	Habib-Ur-Rehman

The post survey sample (10 respondents)

Interview ID	Age	Gender	Marital Status	Children	Other
UK PK Post 1	60yrs	Male	Unmarried	Nil	
UK PK Post 2	70yrs	Female	Married	3+	
UK PK Post 3	65yrs	Female	Widow	3	
UK PK Post 4	>60yrs	Male	Married	1	
UK PK Post 5	61yrs	Male	Married	3	
UK PK Post 6	65yrs	Male	Married	1	
UK PK Post 7	61yrs	Male	Married	Yes	
UK PK Post 8	>60yrs	Male	Married	2	
UK PK Post 9	62yrs	Female	Married	No	
UK PK Post 10	>60yrs	Male	Married	2	.

10

QUESTIONNAIRE DEVELOPMENT



Introduction

The first version of the questionnaire was based on a review of the existing literature, presented in previous sections of this report.

Subsequent versions of the questionnaire are based on findings from earlier interviews. This represents one of the features of qualitative research where investigators are able to change the research instrument as the research progresses.

This approach means that interviews can focus on issues emerging from the findings being made from the research.

Review of Interview Schedule V1.0

This set of interview questions is based on the literature, and the interview schedule is relatively open-ended with respondents being asked to answer in general terms about the impact of social relations on health with scope for probing where they talk about issues related to the constructs of interest to this research.

We also take into account the need to deal with cultural issues, by leaving open the opportunity to probe where respondents refer to issues of interest. The final part of the interview schedule deals with inter-ethnic differences.

Interview schedule V1.0

Part One

In what ways do your relations with friends and family affect your health?

Part Two

Probe areas identified in Part One that link specifically to the following:

1. **Tangible (instrumental)** support e.g. helping with home chores, providing transport etc. Positive social interaction is in terms of dinners, parties, movies, concerts etc.
2. **Informational** support (process by which other people provide information advice and guidance)
3. **Emotional** support e.g. approval and esteem given by another person, and a mutual provision of a 'climate of understanding'.
4. **Negative** support e.g. where relations lead to stressful events or lead to actions that have a negative impact on health (e.g. consumption of unhealthy foods) or impair the patient's ability to manage their health.

Ask for elaboration on issues that link the above with cardiac health.

Part Three

Ask for elaboration on issues raised so far that link with specific aspects of South Asian culture e.g. hospitality, respect, filial piety.

Part Four

Ask for elaboration on issues raised so far that seem to distinguish responses between indigenous respondents and South Asians.

Analysis of changes to V1.0

Having undertaken the initial interviews we found some specific examples of negative social support and informational support. We decided to probe these further in V2.0. Specifically we asked in more detail about the impact of social customs and obligations, the fact that social network members may exchange news about the patient and people giving incorrect advice to the patient.

We also noted examples of patients offering help and advice to others, so we also tried to probe for that.

We had also found that British Pakistani respondents had experience of receiving medical care and social support in Pakistan from relatives there as well as from British based relatives. For that reason we decided to ask subsequent respondents about these issues more specifically. The reason was that such commentaries often provided insights into the impact on cardiac patients as a result of sub-continent connections.

Interview Schedule V.2

Updated list taking into account feedback from interviewees.

Last updated 19/12/2005

Includes data from UK Interviewees I / II

Part One

In what ways do your relations with friends and family affect your health?

Part Two

Probe areas identified in Part One that link specifically to the following:

1. **Tangible (instrumental)** support e.g. helping with home chores, providing transport etc. Positive social interaction is in terms of dinners, parties, movies, concerts etc.
2. **Informational** support (process by which other people provide information advice and guidance)
 - a. **Shielding effect.** Friends/ relatives may also try and shield the patient from bad news etc. (UK Interviewee No.1)
3. **Emotional** support e.g. approval and esteem given by another person, and a mutual provision of a 'climate of understanding'.
4. **Negative** support e.g. where relations lead to stressful events or lead to actions that have a negative impact on health (e.g. consumption of unhealthy foods) or impair the patient's ability to manage their health.
 - b. **'Innocently negative support'** where people are well intentioned and try to help, but not in the opinion of the patient. (UK Interviewee No.1)
 - c. **Social customs** – in Pakistan e.g. elders attending marriages in order to offer blessings can be a problem, if the elders also have cardiac problems. (UK Interviewee No.1)
 - d. **Relatives can tell others of cardiac problems** e.g. employers told of problems so that they can take this into account when giving tasks to the cardiac patient (UK Interviewee No.2)
 - e. **Wrong advice given by friends/relatives.** Friends had advised that he should not go for walks etc since it would put stress on his heart and this was contrary to doctors' advice. (UK Interviewee No.2)
5. **Support by the patient to others in social network**, patient may have interests e.g. walking and accompanies others who need exercise. (UK Interviewee No.2)

Ask for elaboration on issues that link the above with cardiac health.

Part Three

Ask for elaboration on issues raised so far that link with specific aspects of South Asian culture e.g. hospitality, respect, filial piety.

Part Four

Ask for elaboration on issues raised so far that seem to distinguish responses between indigenous respondents and South Asians.

New issues

UK vs. Pakistan issues

- Greater information availability in the UK. (UK interviewee no.1)
- Addressing boredom in the UK can be via non social support methods such as attending classes. Boredom can lead to habits and activities that are unhealthy e.g. chewing tobacco. (UK interviewee no. 2)
- Argument that stress levels greater in Pakistan than UK (UK interviewee no. 2)

Analysis of changes to V2.0

The changes made to this questionnaire were as follows. We identified that we needed clearer grounding, right at the outset of the interview, from the patients as to what they had been recommended to do by the doctors and that this would provide a baseline in terms of seeing how their subsequent lifestyle deviated from this. It would also help to put into context the information that they were being provided by their social network members.

The way in which these new questions were to be asked was from the general to the specific, so that the respondents were given as much opportunity as possible to identify key issues from their own perspective. Only if the interviewee did not understand the general direction of the questions, would we ask more specific questions.

The style of the questions in this version was also somewhat different to the earlier versions. We now knew the best way to ask questions about a particular topic – which would be as meaningful as possible to the respondent and enable them to give a full answer. In this manner we were able to transform the general constructs, emotional support etc. into more meaningful and practical issues to which people could provide specific answers.

We were also able to place the constructs in the contexts of people's everyday lives and this allowed us to ask about specific situations – which could enable more precise recall. For example, we asked respondents about what they talked about with relatives when the latter first came to visit them. This enabled the respondents to think back to a specific situation.

We also asked about information support in terms of any specific items that had a profound impact on the patient. The idea here was to help their recall by just focusing on the most memorable piece of information. Negative support also had a more specific context, people being overcautious than had been the case at the beginning.

Interview Schedule V3.0

Last updated 25/02/2006

Specific Questions to be asked

Background questions (these questions help establish the benchmarks for comparing answers to future questions)

1. In your mind what could be the possible risk factors leading to this problem?
2. What kinds of precautions did the doctors advise you after the bypass?
3. Did your doctor gave you any specific advice regarding food and life style changes? (in case the previous question does not yield useful answers).
4. What do you see as the most important issues in your managing your heart disease?
 - a. If patient needs clarification mention that it is to do with the advice doctors gave when the problems started.
 - b. If the respondent is still not sure say that it is to do with taking medicines, exercise, diet, managing stress etc.

Personal lifestyle changes

5. What changes to your lifestyle have you undertaken after your diagnosis?

Emotional Support

6. What does emotional support mean to you?
7. After your heart attack did you feel that there was someone there for you to provide emotional support (and what form did this take?)
8. Can you describe any situations to me when someone provided emotional support to you?

Tangible Support

9. Did your relatives or friends do anything special for you once they came to know that you are a cardiac patient?
10. How did your family support you?
 - a. Ask for specific examples where possible
11. Have you experienced any change in people attitudes / actions now as you have heart disease e.g. that they have become more conscious when it comes to telling some news to you?
12. After your cardiac event can you describe how the lifestyles of anyone else that you know change, because they wanted to help you?

Informational Support

13. After you were taken ill – the first time that people came to see you, what did you talk about?
14. How did you gain awareness / information regarding your heart problem?
15. Do you have any friends / relatives who also have heart disease?
 - a. (If yes) When you meet these people what sorts of things do you talk about
 - b. If respondent gives no details for the above ask: what information have you given to others who you have found to be suffering from heart disease?
16. Can you remember a specific situation when someone said something and it had a profound impact on you (your lifestyle)? Please tell me about it.
17. Did you at anytime feel that the advice being given to you by your friends and relatives was different to the advice given to the doctors?
 - a. Ask for examples of differences
 - b. Ask for reasons why they think the advice was different
18. Does the education level of children / relatives have an impact on the support that they are able to give?

Negative Support

19. In your opinion, were friends/relatives at times 'overcautious' when it comes to dealing you?
 - a. If the respondent is not sure what we mean, say that it is to do with them being more careful about, for example, diet than the patient thinks is necessary.
20. Do you feel that there are some attitudes/actions of the people around you, because of which you find it difficult to adopt a lifestyle that your doctors have recommended?
21. Can you give any examples of people being a negative influence on your ability to manage your heart disease?
22. Do you feel there are any social customs which make it more difficult to manage life as a cardiac patient?
23. Have you had instances where your close friends and family have told others about your condition?
 - a. How did you feel about that?
 - b. Can you describe the situation?

Final Question

24. What was the role of your friends and relatives when it come to living your post heart attack life, was this a positive influence?

Analysis of changes to V.3

By this stage we had a bank of questions that were generally quite effective and the changes made to version 3 were very limited.

For example, rather than asking about risk factors we asked the more general question about what it could have been about people's lifestyles that had brought about the cardiac event. As with the earlier changes this enabled the responses to be better grounded in people's everyday experiences.

We also now asked about the major events that had occurred in relation to people's heart, this allowed us to gather more medical information about what had happened to them.

Interviews Schedule V4.0

Last updated 25/03/2006

Specific Questions to be asked

Background questions (these questions help establish the benchmarks for comparing answers to future questions)

1. Please describe the major events that have occurred in relation to your heart?
 - a. If patient needs clarification say that we mean, heart attack, bypass, angioplasty.
2. In your mind what could be the possible lifestyle factors leading to this problem?
 - b. If patient needs clarification say that that it could be things such as stress, diet etc.
3. What kinds of precautions have doctors advised you to take regarding your heart condition?
 - c. If patient needs clarification, ask whether their doctor gave them any specific advice regarding food and life style changes?
4. What do you see as the most important issues in your managing your heart disease?
 - d. If patient needs clarification mention that it is to do with the advice doctors gave when the problems started.
 - e. If the respondent is still not sure say that it is to do with taking medicines, exercise, diet, managing stress etc.

Personal lifestyle changes

5. What changes to your lifestyle have you undertaken after your diagnosis?

Emotional Support

6. What does emotional support mean to you?
7. After any heart events please describe any emotional support that you felt you received – and who did you receive it from?
8. Can you describe any situations to me when someone provided emotional support to you?

Tangible Support

9. Did your relatives or friends do anything special for you once they came to know that you are a cardiac patient?
10. How did your family support you?
 - f. Ask patient for specific examples where possible
11. Please describe any changes in peoples' attitudes/ actions now as you have heart disease e.g. that they have become more conscious when it comes to telling some news to you?
12. After your cardiac event can you describe how the lifestyles of anyone else that you know change, because they wanted to help you?

Informational Support

13. After you were taken ill – the first time that people came to see you, what did you talk about?
14. How did you gain awareness/information regarding your heart problem?
 - g. Supplementary question: some of the people we have spoken to get information from friends and relatives, others get it from leaflets and television. Can you explain why there may be a difference?
15. Do you have any friends/ relatives who also have heart disease?
 - h. (If yes) When you meet these people what sorts of things do you talk about
 - i. If respondent gives no details for the above ask: what information have you given to others who you have found to be suffering from heart disease?

16. Can you remember a specific situation when someone said something and it had a profound impact on you (your lifestyle)? Please tell me about it.
17. Did you at anytime feel that the advice being given to you by your friends and relatives was different to the advice given to the doctors?
 - j. Ask for examples of differences
 - k. Ask for reasons why they think the advice was different
18. Does the education level of children / relatives have an impact on the support that they are able to give?

Negative Support

19. In your opinion, were friends / relatives at times 'overcautious' when it comes to dealing you?
 - l. If the respondent is not sure what we mean, say that it is to do with them being more careful about, for example, diet than the patient thinks is necessary.
20. Do you feel that there are some attitudes / actions of the people around you, because of which you find it difficult to adopt a lifestyle that your doctors have recommended?
21. Can you give any examples of people being a negative influence on your ability to manage your heart disease?
22. Do you feel there are any social customs which make it more difficult to manage life as a cardiac patient?
23. Have you had instances where your close friends and family have told others about your condition?
 - c. How did you feel about that?
 - d. Can you describe the situation?

Final Question

24. What was the role of your friends and relatives when it come to living your post heart attack life, was this a positive influence?

Review of questionnaire development

Overall the changes that have taken place have allowed us to move from asking about broad themes towards asking about more specific issues. This meant that the extent to which respondents could talk meaningfully about key issues improved over the course of the survey. This also meant that we were able to focus on issues that had arisen in earlier interviews in those interviews that came

11

TANGIBLE SUPPORT



Introduction

Respondents talked about a number of different ways in which people offered them tangible support. In the text below we consider some of the major and sub-categories of such support.

The major topics covered in this section are:

- Medical care
- Lifestyle
- Exercise
- Who provides the care?
- Negative support
- Links between tangible and emotional support

Context in which the help is offered

Medical Care

One of the first instances in which the patient may need tangible support is when they are having what seems to be a heart attack and they need urgent medical attention. The following quotations show how the families of different patients dealt with the situation:

Trip to the hospital

I told my sister and nephew that I was just not feeling good, it was then when the pain started in my chest giving me a clue that it could be a cardiac pain. They then took me to the hospital, in emergency the doctor did ECG

UK PK Post 8

Thus I told my sister about my pain, at that time nobody was at home at that instant my brother-in-law came. Me and my sister went to emergency to a nearby hospital in his car. When I reached the hospital they did ECG but it had no changes as they told my brother-in-law after sometime they discharge me

UK PK Post 9

I was playing with my grand children in the back of our house, fortunately that day my son had came to see me, when he saw my condition he become worried & immediately asked me to accompany him to the hospital.

UK PK 8

I can't remember who took me to hospital 20 years back. I think that was one of my office friends who took me to the hospital, as I was just not feeling well. Five years ago my wife called the ambulance, which came immediately and she accompanied me to the hospital.

UK PK 9

I was driving with my daughter and I was having this difficulty in breathing so my daughter called our doctor who asked her to immediately take me to a hospital and that he is coming there to see me. I am talking about the second time. My friend was a doctor who we called and he asked us to go to hospital and before we could reach hospital he was there

UK PK 19

No I never face any difficulty because my brother has his own car so he always took me to hospital.

UK PK 6

One of the ways in which tangible support can be offered is helping the patient with their drug regime. This can involve making sure that the medicine is taken at the right time and also that the possible side effects are known (the latter issue links with informational support). Some patients also referred to relatives who were in the medical field and who offered tests and assessments etc. on an informal basis.

...drug regime

my son he is always reading the prescriptions of my medications which came with the pack and have all the information about the medicine and after reading that he keep on telling me there side effects and that helps once I had this skin rash and he told me that it could be due to that ibresartan

UK Eng 12

I usually take my medication on time as my wife keep on asking me have a taken them or not. Regarding exercise I do go for walk daily. I try to have a hour walk daily but now gradually as this problem is aggravating it's making it difficult and difficult to carry on my routines but even if I have no energy I go for walk even if I walk 15 minutes I walk as I don't want to lose this habit of mine.

UK Eng 16

He always took care about my medicines. He was the one who encouraged me to go for a walk.

UK PK Post 9

My son gave everyone in the house a job to do for me and that really supports me. For example his job is to take care of my medicines he brings those in and he considers it his responsibility that I take them.

UK Asian 5

He has made a tablet holder in which holds my 7 days a week tablets. In it he wraps the tablets as morning, evening and night doses and put them into piece of paper and put them into there respective days in that holder. When he comes back everyday from the job he checks that if I have had my medicines or not.

Asian 5

They take care about my medicine time and my wife start cooking in corn oil.

UK PK Post 4

I had 3 sons but only one is taking care of me when was admitted in the hospital he visited me daily he cares for me a lot he bring my things and medication for me.

UK PK Post 5

As the following quotation shows tangible support relating to the drug regime can be perceived as being negative where the patient does not feel that what is being offered will actually be of any use.

I have got such silly things from learned fellows that I have changed my mind now. For example one of my relatives who teaches in a school and is quite a learned person came to my home and gave me a bottle telling me to drink it everyday after waking up first thing in the morning according to her she had got that from some religious person who has done something to that water which will fix up my disease

UK PK 15

For some patients tangible support can also involve family members helping with some basic diagnostic tests at home.

...tests etc. at home

I knew that something was wrong in me so I asked my daughter to check my blood pressure as I am a high blood pressure patient my daughter told me that it was high so I slept

UK PK 12

when my husband tried to count my heart speed according to him it was nearly impossible for him to count then as there were so many of them and I am so happy that he was right as when we reached to the emergency and doctor there recorded my heart speed he told my husband that it was going dangerously fast

Asian 8

Smoking cessation

A key piece of advice for cardiac patients who smoke is to quit completely. We see below the different ways in which friends and family members of patients have helped them to make this important lifestyle change:

Yes, it was my husband he was a chain smoker he quit smoking because he wanted to stop smoking, which helped me a great deal in quitting this habit of mine.

UK Eng 4

They have given me support to quit that habit of mine my son once took me to an smoking cessation clinic, my daughter bought those patches for me as well. I have promised them to stop smoking from next month

UK Eng 12

Neither of us friends smoke now, one of them the same one I telling you about, has died so we are 3 who are left now. We drink but only on occasions.

UK Eng 20

Where relatives do not change their behaviour it is interesting to see the negative reaction of the patient:

Where relatives don't change

Yes it is the habit of my wife, which doesn't help me much to adapt what everyone asks me to do and that is the smoking. Due to this habit of hers I really find tough to quit smoking completely.

UK Eng 7

Yes first the attitude of my friends and then my wife, these two things have made it impossible for me to quit smoking. Nearly all my friend smoke and in my house my wife is a chain smoker and my son smokes how do think that it is possible for me to stop smoking?

UK Eng 8

It should be noted that Asian patients did not talk about smoking, quitting and the role of partners in this.

Change in Diet

Following a coronary event patients are often advised to change their diets. The suggestion can be that they reduce consumption of red meat, with preference given to white meat and generally reduce consumption of saturated fat. In the quotations below we can see how patients' friends and families cope with those recommendations and how patients negotiate the advice that they have received with the cultural norms that they have to face.

The first issue that we can see is the difference between situations where there are no dietary changes made in the family (and the patient is left to their own devices regarding what to eat) to situations where dishes are made specifically for the patient and the other extreme where changes are made for the whole family.

No changes **DIMENSIONS – LEVELS OF SACRIFICE**

No they never used to make any special dishes for me and I did not even ask them to make for special dishes. I used to select the food which was good for me e.g if there is food there which has lot of oil in it I know that that will give me heart burn so I tend to avoid it. If the food is too spicy I try not to eat much.

UK PK 18

This is because of our family. Will all your family eat what the doctor asks you eat? No they will not so you will continue to eat what your family eat - the same oily and fatty stuff. You cannot cook for everybody separately so you will cook all the same thing, the rice, the curry and then there will be lot of spices in the curry.

UK PK 19

but if anybody invites me then they don't cook anything specially for me they cook what they want, they don't even give me sugar free tea. Nobody cares, you have to avoid all things by yourself because it is you who has suffered from that chest pain, you have gone through the bypass, you know how it is. Then you have to avoid, not them.

UK PK 10

our community is very unsupportive when it comes to helping people in following advice. For example our community don't care what to cook when they invite any heart patient, while the English person will not ask any heart patient to come if he thinks that that food will be unsuitable for him or he will tell the patient before about the menu so that you can arrange yourself some other thing. Such as if they are organizing a barbecue they will tell so that you can arrange something for yourself, prior to coming but our community first they invite and then they insist you eat those things

UK PK 10

The following patient gave an explanation for this observation:

In Pakistan you cannot change your lifestyle after your heart attack the food being served there is impossible to eat and people eat them the people there are not serious about there disease as they have a joint family and cooking for a single person is impossible there I am taking here about the average family and not the rich family

UK PK 18

Changes only or specifically for the patient

At the start when they use to ask me for dinner they used to cook fish for me beside other normal dishes but this was not their normal routine, this only happened sometimes. It was not that different. I never realized myself that I had a heart attack and nor did my friends and relatives do anything which would have made me realize.

UK PK 2

I was having plenty of grilled food, which my wife used to make for me, as she knows that I needed to lose a lot of weight. I was eating that even before that heart attack happened.

UK PK 19

They ask me what will you prefer eating? They will then make that and give it to me as they know that I won't eat all those things with cheese and everything.

UK PK 19

They used to treat me in a very good way that do this and don't do that that's not good for you and that you should refrain from it but did not use to like it e.g that that I should have dinner early then them as they use to eat a bit late but I don't like this.

UK PK 18

Whole family diet change

To be specific the family have to suffer even more than the patient as they have to eat all those things, which the patient does. If they don't do that then the patient cannot maintain his appetite in other words it has a positive effect on their health.

UK PK 13

Yes my wife and my son both supported me, in fact I just have to follow what my wife was following before. I guess it is my son who really has to suffer a lot as far as food is concerned as now he has to eat what we two eat.

UK PK 15

My wife cooked food in corn oil and we all eat same food, low fat diet and she uses white meat like fish, chicken. Some times my daughter cooked food for me, my son join me on walk daily to give company.

UK PK Post 8

They all sacrificed for me as their mum used to cook same food for all of the family as she got scared when the doctor told us that the problem could be running in the family. She does not want her kids to end up having bypass one day and it helped me in an indirect way as I think that it would have been very difficult for me hold myself back once I see them eating those tasty food. And the whole families acknowledge her idea as it is better to avoid than to suffer.

Exercise - Companionship

What was interesting here was the variety of people that patients referred to as providing companionship for exercise. The different types of person form the basis for the categories provided here. As can be seen, these range from family members to people outside the immediate social network of the patient.

Family exercise companion

For providing me company, my husband walks with me so that I don't feel alone. My husband has supported me all these years and I think that has helped him as well because he is now going for a walk, eating healthy food etc. by doing this unknowingly he is helping himself to avoid from lots of diseases

UK PK 10

I have cut my meals & I am eating less rice now & initially I used to go for a walk daily with my husband but now I am not going for walk daily, my husband asked me to go but I become so tired doing household work that I don't go.

UK PK 7

Neighbour exercise companion

it was Mr. Smith who forced me to go for a walk with him as he is a heart patient himself but on the contrary he really takes care of himself. Even I was not that careless of my health but after my wife's death...

UK PK 14 (note that difference between emotional and tangible is actually doing it)

Pet exercise companion

I know that I have to go walking because it is my dog's requirement, you have to have some motivations in life in

order to keep you moving. And for me my motivation for walking is my dog.

UK Eng 6

Friend exercise companion

but now I join the gym regularly because of my friends. They were not good at exercise but now we have decided that we will meet twice a week at the gym rather than meeting at someone's house and we will chat after doing some exercise. Actually it was my idea, I think by doing this both of them are at least doing some exercise. It don't benefit me as much as it benefit them but then that what friends are for.

UK PK Post 4

I could not do the exercise initially but then one of my friends asked me to join him on the golf course. Since then I go to play golf regularly, this way I do my exercise as well as keeping an activity going which helps keep a check on my weight as well.

UK Eng 12

... exercise companion from cardiac rehab programme

some of my friends with whom I was in contact even after we got discharged were not asked to attend the session so I phoned T C who was the cardiac rehabilitation nurse at that time to invite them in that session. So that session was a very good place to be, it was a nice experience to see some of those patients who were there admitted with us in the hospital fighting for their life, doing exercise in front of you and smiling

UK Eng 20

I made two friends there. We went to rehabilitation group together, I must admit here that I attended the group because of them. One of them used to come and pick me up. My daughter-in-law used to get very annoyed with her at time but she told my daughter-in-law that she will call police if she will worry me any more. Since that day my daughter-in-law does not misbehave with me that much and if she does I tell her that I will tell my friend about her behavior.

UK PK Post 2

It should be noted that where Pakistani respondents referred to walking with people outside their immediate circle of friends and relatives, this was usually the case where for some reason they did not have access to friends and relatives.

There are implications here for making people aware of the possibilities of the range of people that they can work with when it comes to exercise and that they need not restrict themselves to immediate social network members.

The following respondent made an interesting comment about the way in which working with exercise companions may need to be 'managed' by the patient, in order to make sure that the exercise itself is not compromised, for example if the companion does not arrive.

Importance of not relying on others

The important point which I missed is that never rely on anybody to go for a walk. If she won't go then I won't go because if you rely on her and she is not going you will definitely fizzle out that. Ok if she is not going then I also should not.

UK PK 18

A number of respondents talked about family members either buying exercise equipment or helping to move it so that it could be better used by the patient:

...purchasing equipment **CONTEXT**

Yes, every doctor has given me some very useful advice, which has helped me to come this far. Now I know that I have to avoid sweets & salty foods, avoid oily food & red meat & I have to exercise. For that my nephew has bought me a jogging machine, as I was not very keen to go out of my home and then walk. I found it very boring & thus I bought myself a jogging machine we have placed that machine in our living room now I exercise regularly on that while watching television.

UK PK 9

Yes my wife seems to worry a lot by these frequent hospital admissions she wants me to take care of me and follow doctor's advice she is the one who has pursued me to join that she uses to go there and she keep on telling me what a good place it is and how good it's swimming pool is which attracted my attention to go there then last month on my birthday she gave me it's membership card as a birthday gift

UK Eng 8

Yes I did. My husband purchased an exercising machine and I used to do my exercise on that

Asian 8

I had my exercise machine placed in my room but then it was all to boring then my son put it into the lounge room, now I don't feel that I am doing something just because I have to do it. I do it while seeing the television

Asian 10

Everyday Activities - Companionship

In this section we deal with the changes that have been made to the way in which the patient's household is run, in order to help the patient deal with the lifestyle changes that are necessary.

... family members provide care

My children were shocked, they told me not to smoke any more they both hate smoking, my sisters took care of me since my husband died.

UK Eng 3**Family members help with household chores**

My family help me in all my hard work they lift things for me, my wife sometimes does digging and mowing for me and children sometimes do dishes.

UK Eng 7**Family members help with business**

Yes, my family do care about me, my wife doesn't want me to pull any heavy things, she help me in my job she takes my calls while I am in a hospital. My son tries to supervise small jobs which are of his standard. He is always calling me to know when I am coming back to home.

UK Eng 7**Family members help with cleaning**

After my illness my daughter and daughter-in-laws never allow me to do any thing they make 'perhaizy' (healthy) food for me

never give any strain to me they know that if they didn't clean the house I will do it thus they now clean the house in time.

UK PK Post 3

Family members help with driving

My family supports me in all aspects they can. They don't want me to do any work or carry any heavy weight they don't want me to go alone to an place which is far from our home even though I have got my driving license back now and I can drive but they don't allow me. My wife always cooks different food than the rest of the family even though now more than 10 years have passed. But even then for her it is those days when I came from hospital I guess this all was very essential as I had this heart attack at the young age of 49.

UK PK Post 7

Physical changes to property

Yes my sons helped us a lot, they helped us to make a new bathroom downstairs beside that once they come to see us they tried to do as much work for us as possible such as cutting our hedge & mowing our garden etc.

UK Eng 6

One of the ways in which families have sought to accommodate the needs of the cardiac patient is to reduce the demands made on the patient in terms of household chores etc.

Family not asking for usual help Context

but now I don't do all this, she does not demand from me any such thing now, but initially she used to call me asking me to come to her house as I have to go somewhere or can you go and pick up the kids from school but now she does not ask from me anything as now she knows that I would not do it.

UK PK 18

I cannot do all these things and that had put a burden on our family as now my husband has to do all these things he drop the girls at the bus stop and then picks them up later in the day. He is the one who goes shopping now, along with me but it not as good as it used to be once you are on your own. I used to enjoy shopping a lot that is why I used to go there twice every week but not any more.

Asian 8

most important thing in managing my heart disease has proved to be my starting a job. This way I pass most of the day at my job and in the evening when I am at home my husband and my daughter are also there to give me company. My son comes everyday to meet us as well. He lives nearby, his wife is also very cooperative so I don't get all that time to think.

UK Eng 15

A possible aspect of negative support here was the observation by some respondents that their families were trying to do too much and they did not like it.

For some respondents an important aspect of lifestyle change was that they were doing things more often with their partner or other individual such as a friend or relative. In other instances the patient has instigated a change (starting a job) and the family have changed their lifestyles to accommodate.

Keeping to time

My immediate family do support me, I don't see any visitors after 10:30 pm I try to avoid any visitors in night. Friends if

they know, they don't come after 10pm. If some one comes late they come because they don't know my timings.

UK PK 1

Because we don't want to change ourselves we are just living a undisciplined life & want to carry on living like that. Our community here is very non-cooperative e.g. I invited one Pakistani family for dinner in my house just this month & they came in my house at 10:30 PM in the night. While I follow doctor's advice to eat food at 8:00 PM but the guests don't come. The community here is even worse than the community in Pakistan because even in Pakistan if you invite someone for dinner that person usually comes in for the dinner as late as 9.30 PM but here coming late is routine and they are not even ashamed.

UK PK 7

I, myself, used to go to my shop usually accompanied by one of my sons by that way I was keeping myself busy when I had to go to see the GP my son or my nephew used to go along with me.

UK PK 17

I use to go for a walk quite regularly then I used to work in my garden every other day in order to keep me fit. Regarding food I usually liked eating vegetables and so does my Mrs. We prefer having soup for lunch and then go for a walk in the evening followed by dinner. We usually have the dinner by 6pm and then watch television have a glass of milk and retire to bed at 9 pm.

UK Eng 14

I am working in garden; she joins me and shares the load, she has started cooking food in olive oil

UK PK Post 10

My husband is responsible for going on walks with me, he makes sure that I walk everyday. By that way he also does quite a bit of walk and I feel the fresh air. My daughter-in-law is responsible for my food. We both work to make food. Sometimes she cooks if she has time or she cooks it half and I finish cooking it. Sometime if she is working overtime I cook for her.

Asian 5

O yes we are, after discharging from hospital he called me at home to ask how my health is then we made a plan to go to the library together to find out what went wrong with. Actually it was his idea as we knew by that time lot of things in bits and pieces but it was all like a jigsaw puzzle where nothing is making sense so then we looked in the different books which we could understand and tried to bring all the puzzle together so that we know for sure what went wrong with us, what was done to us and how we could prevent it from happening again. And if it happens again how could we know that we are getting ourselves into big trouble and what could be it's consequences.

Asian 6

He used to think about me and my needs, he used to purchase things for me he knew that I like decorative things and I love to spend time with plants so he also used to buy plants for me, if he find out that I am irritable then he would come to me and ask what happened.

UK PK Post 2

Mr. Smith; he is the person who is helping me a lot. He comes in the evening to my house or he often calls me to his house for coffee then he take me for a walk to Tesco. He always has to buy something when I am there this leads to my exercise done this way and by having a good chat with him I feel relaxed and fresh. He is a nice neighbour.

UK PK 14

Support Levels

Too much or too little care

The levels of care that people commented on ranged from 'too much', to 'too little' and also included a reference to a subtle level – which is consonant with the observation elsewhere that sometimes care can be stifling for the patient, but where it is subtly provided it does not cause the patient anxiety.

Too much care

If I would have been in Pakistan my sister would have provided me everything on my bed and I think that's wrong.

UK PK 5

Yes, they have they force me to sit when I don't want to. The worse thing was when my aunt who is herself 75 year old helps me to stand. It really annoys me a great deal, and due to that I have asked her to stop doing that.

UK Eng 1

Emma once said that she wanted to do a job as I was very tense because I am losing my job. That really got me quite upset I could not understand why is this happening to me

UK Eng 18

I did not like getting food from my friends in the hospital. It adds an added burden on me as the nurses don't like you to eat anything from outside, beside that if someone is sending Qorma and Biryani to the hospital how can you eat those things? We don't have the privilege of a separate room, there are 4 to 6 patient in a room and sometimes it is really awkward for you to eat those things in front of all those patients.

Asian 8

How the care is offered **SUBTLE/PERFUNCTORY**

My wife always cook food which I like and we all eat the same food but sometimes when she cooked some traditional food then she used white meat & decreased the quantity of oil. She always take care of my medicine timings without showing that she is concerned & she never forgets. She just observes, have I taken my tablets or not? Or have I gone for jogging or not and if I am not following my routine only then she intervenes.

UK PK 12

Where family members' tangible support fell short of what patients felt they needed, patients were in some instances understanding and ascribed various reasons for the lack of tangible support.

Factors affecting support delivery & perception

Un/Acceptable limitations

my wife has always stood by me, she is also very old and so she can't help me much physically, but she is always thinking for me. She always has some new plan ready for me which could help me be active e.g. this idea of selling our car in order to keep me moving and going out for a walk with my dog really helped me a great deal to keep me fit and mobile

UK Eng 6

Beside my husband and my son also provided lot of support to me my husband is very old my son is himself 33 years old, the problem with them is that they can say to me that I shall not do this or that as I don't do much myself due to rheumatoid arthritis.

UK Eng 1

My family and my church for which I used to preach supported me a lot. The guys from church keep a check on me as to how I am doing and whether I need any help or not. Beside that my wife has always been with me. All this year she herself has not been 100 per cent fit but even then she does as much as she can do for me... the most important thing she does for me is to drag my wheelchair. It sometimes puts too much strain on her arms as I have gained quite a bit of weight recently.

UK Eng 13

My whole family has been very supportive they all try to help me in whatever way they can. Everyone has done his part but in today's world life has gone to be go fast that it's getting hard to keep your relationships going. But all of them have done as much they could have for me.

UK Eng 16

No there has not been any change in the lifestyle of anyone. My son has moved closer to my house I guess that is the only change that has occurred, besides that everyone is the same. They are living their lives in a way they want I never intervene in their lives.

UK Eng 16

In India and Pakistan there are our neighbours and then our relatives who can share the burden but here this is not the case. Here if my family has to take responsibility of me. While I am in the hospital there would be no one to support my wife and my elder son which is not the case back in our countries.

UK Asian 2

Everyone is same why would anyone need to change his life for me and why would I want him to change his life for me? I have had heart attack I have not gone out to be blind that I would need anyone's help. I am still quite capable enough to take care of myself.

UK Asian 1

... use of paid-for staff **SUPPORT IDENTITY**

My family has provided me servants for everything. They do all my ironing and care for my every requirements besides that we have a cook in our house along with a gardener, I asked my husband after my heart attack to arrange a dish washer, which he has

UK Eng 1

... move to sheltered accommodation **SUPPORT IDENTITY**

Sheltered Accommodation with my wife, which has eased quite a lot of burden from my shoulder as now I don't have to look after the lawn and don't have to take care of a big house. It helps me conserve my energy, my other daughter lives in London she along with her husband do come to visit us on a regular basis, now I only have to care about my small apartment.

UK Eng 9

Then when I went back to Essex my daughter there came to see me. She came every weekend to do the hoovering as my wife is herself not healthy, so no one can do the hoovering in our house. Then she arranged the sheltered accommodation for us. All these things have a positive effect on me.

UK Eng 9

When I went to Pakistan after my heart attack my whole family cared for me, specially my sister she used to make special food for me, never allowed me to do any thing extra or which is not good for my heart.

UK PK Post 9

Proximity

The following respondents talked about relatives being relatively close by and therefore being able to help:

After coming from there I went to live with my daughter who lives in the east zone. She came to my house and took me there so that I could recuperate.

UK PK 16

My son has moved near our place he keeps on coming every now and then if he is going to market he ask if we want anything. He brings most of the things in our house, if we want to go anywhere and he is on holiday he takes us there or he asks his wife to take us. They are both very helpful. My other children keep in touch with us, especially their mum.

UK Eng 16

As he knew I take tranquillizer to help me sleep he used to take the keys along with him & there was one time he forgot the keys then he didn't came home in night, he waited for morning to come.

UK PK Post 2

My sons live with me so they have taken most of my responsibility as now they go out for shopping with their mum they don't bother me for this anymore.

UK Asian 2

If we are invited anywhere they opt to go there by themselves rather than taking me with them as they know I am not comfortable in those long parties.

UK Asian 2

In the following instances distance was proving to be an issue in terms of the relative(s) being able to provide help:

I got support from my husband but he does not live with me anymore then my daughter she supports me as well.

UK Eng 17

No-one's life has been changed because of me. My daughter is coming to see me after 11 years from South Africa, that is the only change that is coming in my life after the death of my husband.

UK Eng 19

Expectations due to role / actions

He does not care for me. He is playing in the hands of his wife. His wife has forgotten who she is, from where does she belong? Now she call herself English, but there was a time when she came from Pakistan, she did not even know how to talk to people. I gave her courage and now look what she has done to me and my daughter.

UK PK Post 2

My wife did come to see me along with my son, once I got this heart attack she stayed for couple of months so that I could start managing my things. After that we both went to USA as she wanted to stay there.

UK Eng 11

I think that they didn't care because they know that I am not feeling well but because of their fighting I again shifted to hospital. After my husband, nobody cares about me and now your son is not yours he thinks about his wife and family, not for me. All my daughters are married and they are busy in their lives with their children, they come to me once in a month or twice but not daily. When they come they make food for me because they know that I cooked my food by myself so they make many different dishes for me because at this stage of life I can't work.

UK PK Post 2

My other children didn't care for me. They think that I didn't do anything for them they didn't know that I spent my whole life on them. I have now crossed 60 managing my life with them trying to provide them everything but this is what I have got.

UK PK Post 5

In Bangladesh they need lots of money every year to meet the requirements of life and I try sharing their load as much as I can. This sometimes starts a fight between me and my (immediate) family as they want me to stop sending them the money abroad and give them a better life here.

Asian 3

I have a lot of stress as we were not financially well at that time and the whole responsibility of my family was on my shoulders.

UK PK Post 3

Help from neighbour **SUPPORT IDENTITY**

The boy who just came is a Jew his wife is a Christian they are our next door neighbour. If anything happens to me e.g. heart attack or any pain then he is the first person to come too help.

UK PK 16

...non help **INSUFFICIENT HELP**

No, my son was there when I was in hospital, then he got back to his routine and I got back to mine. He often visits me but I think that is not enough, well I don't need any pity anyways.

UK PK 14

Like my whole family came to see me while I was in Royal Liverpool Hospital and that was the last time I had seen them all together.

UK Eng 17

Impact on feelings

Because of this angina I hardly can walk. I am dependent on my family to do everything and it's not a good feeling. All my social life has finished and it's such a pity for a man who used to talk to at least hundreds of people in a day

UK PK 17

12

EMOTIONAL SUPPORT



Introduction

In this section we look at emotional support and the role it plays in the lives of cardiac patients and the influence it has on them. We first of all look at their own definitions of the term.

We then look specifically at the role of 'encouragement' as a form of emotional support. It should be noted that encouragement is cited as a form of emotional support because it need not involve any tangible support and not does it need to involve provision of information.

We also consider religion as a form of emotional support, because of the benefits that some patients cited on receiving emotional support that had a religious angle.

Other forms of emotional support are demonstrating that the friend or relative understands the patient (in terms of their situation) and also that they display emotion.

What is it?

Some respondents were asked to define 'emotional support', so that we could better identify what it was they were referring to when they answered subsequent questions about receiving emotional support from others.

...sharing thoughts

Emotional support is nothing but sharing your thoughts with others

UK Eng 1

...not being alone

It is a feeling that you are not alone there is some one to help you in your bad times. You are important to someone just as he is important to you.

UK Eng 4

For me emotional support means, by the way that is a difficult question, let me think, may be it's love and understanding

UK Eng 5

To me emotional support means thinking for others without thinking for yourself, having a cheerful time without any worries, the things which have to happen will eventually happen, we can't do any thing for them

UK Eng 7

...feeling important

I received emotional support from all my family; they came to see me every single day while I was in hospital. That had a very positive effect on me as I felt that I am important.

UK Eng 9

Yes from my partner he was there when I was getting my treatment in that ambulance, then he was following me in his car on my way to hospital. He was the first person and the only person till now who came to see me while I was in CCU and then he came daily in the hospital.

UK Eng 2

...being there

For me it means that some one is always there for you. To hold you in his strong arms, providing you courage to fight your problems. Always giving you an impression that if something happens to you that person will always be there with you and will never leave you in any situation.

PK Post 9

Everyone started giving me more time than usual, my husband contacted other Bangladeshis in the locality who were not our friends and told them that I need their company. My son sometimes drops me at their house in the morning and my husband picks me up from there.

UK Asian 5

My grand-daughter just loves me and gives me company after coming from school.

UK Asian 5

I have a well-settled life my children care for me there is no problem of money I have got now my own shop, which is running well

UK PK 17

...care

Because of my children. They give me a lot of courage & care a lot for me and their behaviour shows that they need me a lot so I make my willpower strong

PK PK 15

There are a number of different ways in which respondents talked about receiving social support. It should be noted that one of the respondents identified a limitation of emotional support:

Emotional support is important but the main support is an individual's own support because someone can support you for 2 week or 4 weeks not more than that. But then there would be a time when you have to support yourself. You should be energetic to do anything you want to do. If someone is giving you emotional support after sometime you tell her that you don't need their support and that now you take care of yourself and then show your energy to do things without there help.

UK PK 19

Support Identity

In the instances that follow in the rest of this section we will see that emotional support is provided by family, however there were two instances of patients innovating in order to deal with situations where they needed more support than was available from these two sources.

Patient developing social support from scratch

Mostly I passed my time in gym where I have a lot of friends and especially after my sister marriage they support me a lot. When I again joined my gym they provide me company if I do any sort of hard exercise they prohibited me. We arranged a gathering at my home but meal was not so oily they strictly cared about that and ate the same food with me

PK PK 19

Support from other patients

My first emotional support was given to me by my fellow ward patients. You know once you are in a ward after the heart attack you tend to pass the most time with the patient who is on the bed right next to you or in front of you. I think it's good to discuss your problems with them as they are travelling in the same boat as you are and they at time can give you a lot of emotional support, as well as that you can give something positive to them. It's always good to talk to others.

UK Eng 1

Context

Encouragement

One of the ways in which friends and family offer social support is to provide encouragement to the patient, the following are comments about how patients said they received such encouragement. In the section dealing with tangible support we cover those instances where family members actually made a practical / concrete contribution to the patients' activities.

...for diet and exercise

In my family everybody encouraged me to walk and 'perhaiz', (following a healthy diet) they told me that walking is necessary for a heart patient

UK PK 10

...normality

They didn't let me realize or let me feel that I had a heart attack. They know within themselves that I had a heart attack, otherwise everything is normal they treat me normally, as they treated me before.

UK PK 13

Recovered and looked better everything seemed to be fine then they started to treat me normally they never made me realize that I had a massive heart attack. They tried to show that everything is normal. My relatives also behaved normally as they were with me before my heart attack. I also felt a little depressed but the behaviour of my family and relatives helped me to come out of it. At that time I didn't feel tired but now I can't even walk much, specially after meals & when somebody shouts I feel that something heavy is there on my chest.

PK PK 4

Source of inspiration

I think the most important thing, which was most helpful was given by a patient who was over 87 years old and yet he had the urge to live. I met him in cardiac rehabilitation, I thought if he is willing to do all this at this age then why not me and that was it since then I went for it.

UK Asian 2

My wife and daughter supported me a lot they supported me that I could work like I was doing before this heart attack, they advised me to continue with my job and remain active in life.

UK Asian 7

...cardiac problems to be expected

My relatives also supported me, they said it is a part of life: "Bemari, dukh jan ki zaqat hai" ('illness and pain are charity for the soul'). They said to me that I am a brave man and Allah will make things better for you.

PK PK 5

Force

But my husband forcefully took me to London (for the operation). Everybody was trying to give me courage, some people did ask me to use different medications but I didn't respond to them, then they said I am very strong that I am going through this operation

UK PK 10

moral blackmail

but she said if I eat any thing in front of her which is bad for my health then she will eat it too.

UK PK 11

Role of gift giving

once I got back to my home from hospital my husband presented me with lots of flowers

UK Eng 1

Taking into account others' situation

My sons, they came over to stay with me for the weekend once I got back to my home. They are quite old, one is 41 & the other is 35 years old. They have their own families even then they took time out for their mum, I really acknowledge that.

UK Eng 4

Yes my wife does, she is disabled herself but even then she really cares for everything, even to an extent that I sometimes feel very embarrassed that I cannot do anything for her.

UK Eng 14

Coping with the situation

I received a lot of support from Emma I never realized that she still loves me so much. Everyone in my family got quite scared by this but she managed everything quite boldly.

UK Eng 18

My son takes care of his brother even more now as he knows that he is very dear to me. My elder son goes walking with me, holding my hand, I must say that it a nice change.

Post PK 3

Religion

Emotional support was also received in various forms when friends and relatives invoked religious symbols and concepts when offering support to a patient:

Everyone now seems to worry for me and they pray for me. I know a lot of people and they all love and care for me. They all pray that one day I could come back and preach to them once more. But I guess they are asking too much but maybe I could as only God knows our fortunes.

UK Eng 13

My parents visit me first and they give me a lot of prayers and love and they said, 'don't take any tension, you will be fine'. They told me not to worry and have faith in God, I was so blessed at that time that both of my parents were alive.

PK Post 7

...others prayers encourage the patient

I received quite a lot of support from my brother I use to call him every weekend and we use to have a long chat about everything and that proved to be very useful. He told me that everybody back there in Bangladesh was praying for me, from the time they took me to the operation theatre and till they heard the news that the operation went well and I was out of danger. These little things really gave me lot of energy to fight back.

UK Asian 3

...in order to calm the patient

I can't say that they were giving me advice but they were trying to calm me down they were trying to encourage me not to worry & that everything will be fine. At time of my test I was very worried but my wife stood by me & encouraged me to go for it, she told me that she has belief in God & that God is gracious who will not do anything bad to us

UK PK 8

There are some relatives of mine who are settled here in UK, when they heard about my illness they did come to see me here. One of my nephews who is settled there in Ireland he is doctor he came especially to UK to have my bypass done. He is just like my son, his presence at that time gave me lot of support he was always asking me to relax. His presence made my wife very courageous you know about women they aren't as strong as they think they are. Now he has promised me that he will accompany me to Hajj next year, as I was very sad to miss my Hajj due to my illness

UK PK 9

Allah gives me a lot of courage & He gave me great will power. My husband cried for the whole night before my operation & my son read the Holy Quran whole night & day for my sake

UK PK 10

My wife sat in the ambulance and started praying for me, she told me afterward that our neighbours came after half an hour, they husband and wife both of them are very cooperative

UK PK 11

she also instructed me to read a verse which I remember, she loves me a lot.

PK PK 15

...religion and health priorities

They come to me & asked what's wrong & how has it happened to you? My whole family died naturally not by cardiac disease but my sisters also had heart disease. One of my relatives said don't go to Majlis (religious gathering) a whole day before I was going. I replied I lived because of them so I will go.

PK PK 8

as a means of managing

Yes they encouraged me a lot, in the best way according to the situation. They said that all this is an examination from the Allah & we have to pass this with our steadfast behaviour.

PK PK 13

As well as others providing emotional support to patients, there were instances cited of patients providing emotional support to their relatives. As can be seen sometimes this took the form of invoking religious issues:

Role of religion

They got very tense and nervous. They thought it was very dangerous and life threatening. I convinced them that here the doctors are so used to doing this procedure like a butcher slaughtering the goat and we are Muslim one day we have to return back to Allah and its beneficial there is only 5 % risk associated with it. I said Inshallah (God willing) every thing will be fine if worse come its chance is 5% but 95% is a good chance.

UK Int 5

Idea that people need to be proactive as well

The most important thing is that we are careless we put everything on Allah, that Allah will do this and Allah will do that. We are keener to pray for our health I am not saying that it is wrong but we should also concentrate on following the advice

UK PK 10

They (people in Pakistan) have a lot of query and problems related to family and their jobs. They are living in a stressfull environment. There is also a difference between their thinking, they think all things are done from ALLAH and we can't do anything but we think that we can prevent these things or prevent bad things to be happen

UK PK 11

Visiting others

Yes, most of my relatives came to see me, I am very social person

UK PK 8

Understanding the patient

Patients mentioned how emotional support sometimes came in the form of friends and relatives 'understanding' the position of the patient. On the other hand some expressed exasperation because they felt that others were showing no understanding at all. The latter can be particularly true where patients have friends and relatives overseas, with whom there has been no face-to-face contact for many years, as the first quotation shows:

No, my mum is still fit as a fiddle, she visits me every year as she knows that I am living here alone. She knows it's very stressful for me, she understands my problems so she doesn't bother me.

Post PK 1

...relatives make too many demands

I didn't allow any visitors because they discourage me a lot. They all ask me to return back to Pakistan and get married or even go there to visit them, they think that I am a greedy person who just want to earn money and money and they don't know that I can't go to Pakistan as I am on asylum

Post PK 10

...not attributing blame on the patient

besides that she never blames me any more, for not putting much time at home, as with our children I know that it is all our fault

Post PK 10

People understand situation of the patient

I don't think so, the people here in UK are well-educated & they usual care for other person's concerns & they know that I am heart patient & even then I am trying to come to their place thus they appreciate that I have came regardless of the fact that I am eating their food or not.

UK PK 9

For some Asians the cultural environment in the UK and their ability to cope with it can place particular stresses. This may mean that people worry about the state of their children and there can be particular concerns about marriage. This relates to social support in the sense that some patients may feel that they do not receive the support they expect from their children:

Cultural environment

I think it is the same because they also worry a lot about their family and I think I am not living in a British atmosphere because all my sisters are here with their families so I think I am living in a Asian environment because they care for me a lot they have much time to love me and spend on me.

UK PK Post 6

Emotion

This is a difficult issue to deal with in terms of analysis. It is clear from the sentiments expressed by some patients that where relatives demonstrate being upset, this demonstrates 'emotional support'. However context is important as the following quotations show:

All of my family members got depressed when they knew about my condition, they were very worried and closely followed what was happening in my life, they were always curious to know as to what will happen next

UK PK 10

My son S is very health conscious he use to get annoyed with me if I ate something which is not good for my health.

UK PK 18

In the beginning they were very afraid and they cared a lot, but with the passage of time & looking towards my condition they feel relax and the realization of the fact that this condition can be treated was a calming thought for them

PK PK 5

They are very scared & tense because I never even had flu, so it's really a terrible situation for them and in our culture children are very close to their mother, so my son is also worried

PK PK 15

Firstly, they couldn't work out why I had this pain then they started asking me and then they forced me to visit the doctor. They were really angry, why I didn't tell them? They were really worried about my health

PK PK 16

The time they came to see me and were not told they were thinking that it was anxiety so they were behaving just normally. But when they were told that I had a heart attack they were really frightened, they came and hugged me and kissed me.

UK Eng 3

I knew that if she will have the news that I have got a heart attack she could over-react to the situation, she would tell my elder son who himself is only 16 to come with her and then they would be driving like if they are competing in a Formula One Grand Prix

UK Eng 18

Impact of cardiac event on family politics / relations

A number of patients explained how their cardiac health had had an impact on family relations. This is therefore seen as a possible positive source of social support, though it can be negative as well – depending on how relations develop. As positive social support this can take the form of people who were not previously on speaking terms, re-engaging their social relationships. In other instances an existing relationship may take on more favourable terms for the patient.

Yes their attitude has changed a lot & after my bypass most of my relatives have nearly taken a 180 degree turn in their approach towards me and their behaviour after my bypass changed a lot. Nearly all of my relatives called me and inquired about my health even those relatives who were not having any relations with me since my divorce. After my bypass my wife and relatives started to care for me even more. Especially my nephew who is just like my son. He is now calling me on every weekend & he tries to follow my life's

routine by asking me if I have taken my medicines or not. My friends they regularly come to meet me so that I don't feel alone, so everyone has done his/her bit as much as they can & I do acknowledge them for that.

They are enjoying their life there and we are suffering here, I like to point out that since heart attack the behaviour of my daughter has changed, she has suddenly become more mature and now standing-in between me and her husband's family

UK PK 11

My family has matured a lot with this problem of mine, my son is helping her step-mum just as it is his mom, and I love that feeling. And I want that feeling to carry on. I am satisfied by the fact that if I die they will live together and care for each other.

UK Eng 7

I received a lot of support from my girlfriend then and now my wife she really stood with me and accepted me as I am with all the faults in me.

UK Eng 8

As this patient explains the motivation behind some of the relationship changes can be because of an appreciation on the part of other people that they could have 'lost' the patient.

Due to this heart attack my wife and I have realized our mistakes. Once my wife realized that she could have lost me in this heart attack she realized how it feels after losing someone and she sat with me to talk about our life and as I was bed bound for some weeks I passed a lot of my time with her which made me realize my mistakes

UK Eng 5

It was related to my mother who died in March I was very close to her she could not see her sons fighting for a house in which she use to live I remained with her in her last days she remained in this same hospital for more then 2 weeks before she died as a daughter I was very close to her and I felt the pain she was going through

UK Eng 15

My daughter there in Bangladesh got very worried she tends to call me quite a lot now after my heart attack she calls me on every weekend and I call her on Tuesdays and Thursdays. She initially had this idea that her brother does not care for me and that I is why that heart attack happened. Some of my relatives back there in Dhaka gave her that impression, that your brother and sister-in-law must not be taking care of your mother that is why she had the heart attack. Since then I feel quite guilty as my son has done so much for me and I could not do anything to save his reputation in the family.

UK Asian 5

The following is an example of the negative impact family politics had on one respondent:

My daughter came to visit me at home from Pakistan after almost 1 month of the first hospital admission, my daughter in law and my daughter had a fight on some issue. I didn't know till now why they were fighting but I heard their loud voices and I felt that something was hammering in my head and I started feeling pain in chest. I called my son to stop them

fighting but nobody was listening to me then I tried to get up from the bed and suddenly I fell down after that I don't remember anything till the time I opened my eyes to find myself again on a hospital bed.

UK PK Post 2

Worrying about other people

One of the outcomes of patients' cardiac health has been the realisation on their part that they may have been paying too much concern to other people and that successful rehabilitation might involve being less caring.

If I get tense I try to come out of that situation & try to solve it as soon as possible. Now I have applied the policy to stop worrying about other people, I become selfish and it has solved most of my problems.

UK PK 11

My husband asked me not to worry in that regard, he told me to relax and emotionally calmed me down by slowly convincing me to send my mother to a nursing home. He promised me that we will visit my mum on every weekend and when my mum actually went to a nursing home he used to go & see her every second or third day so that I could relax

UK Eng 4

My children make me feel proud of me every time they achieve or do some thing good.

UK Asian 10

Nobody is bothered regarding my lifestyle. But some of my colleagues said don't be so sensitive...nothing bad has happened to you, the doctor gives the same advice to each and every patient

PK PK 6

Yes I had, related to office work & because of my son he is in US. I am very much worried for his life maybe it's psychological because when he went he was 19 – 20 years old and he is the only son of mine. As a father I am worried for his life, he is alone. What he eats? How he can manage with his surroundings?

PK PK 1

This patient cited concerns about his children's behaviour as being a source of family tension:

It was the problem of my three sons they were in their teens & they were in this habit of excessive drinking and not giving us any respect.

UK Eng 5

The following patient explained how he dealt with the problem of there not being enough emotional support for him:

I stopped caring about others I now only care about me and my family and no one else because everyone else is selfish if no one cared about me and my mum then why would I care about them?

UK Eng 15

Support levels

Negative support

In the first two examples below the patient referred to receiving no emotional support at all. However the subsequent examples are categorised as being 'negative' because instead of providing emotional support to the patient, these friends and relatives actually make the person feel worse.

Even at the time when my family were saying that I am a psychological case he supported me and trusted my words telling me to hold my self and don't let myself down & so did my children.

UK PK Int 7

My brothers didn't support me they come to me on weekends as a formal trip.

PK PK 19

Too little or too much

Too little

My relatives have no role in my life.

PK PK 15

This patient refers to his own lack of concern for other relatives when they had heart problems and therefore he does not think it unreasonable that now they are not concerned:

I knew that I could not give them time as I have to run my own business. Yes, I have two of my relatives who have this problem but they are not that close to me as due to my work I never had time for them and now once I have time I don't want to discuss any thing with anyone I don't like to hear again & again that I have this problem

UK Eng 5

No they don't. I told you about my sister I went to her home because she insists a lot. I have to walk a lot for her house when I reached her building, she lives in the fourth floor and there is no lift. She goes to up on chair because of heart disease but when she saw me she said come up. I love her a lot so I rushed to her house then a pain started in my chest and I felt breathlessness because I walked a lot. I couldn't even take out my tablet. I asked my nephew for help, then I put it under my tongue but nobody asked me to sit and nobody noticed. Everyone in her house made it clear that I am posing and sitting, relaxing and they think I am making a drama in front of them and I need something from them.

PK PK 17

Its all about caring I have 17 children from 3 marriages. My first husband died of cancer, my second husband died in an accident and my third husband died of a heart attack, but I am all alone, none of my children are there with me now I am all alone. None of my children came to see there are four children from my last husband but they did not want to see my face. When their father was alive they used to come and visit our house at that time I was rich, I inherited lot of money from my previous husband. But after the death of their father and

when all the money I inherited finished they never turned back to see if I am alive or dead.

UK Eng 2

Patient's perceptions of social support can be affected by what they consider to be 'expected' levels of support. In the quotation below the patient is comparing his experience to that of other patients. We would argue that this aspect of social support is socially constructed.

...presence of family

See I am lying here alone and there no one with me if you look around me every one of the patients has someone to support them emotionally and I am alone. It's very disturbing, there are times when your family should be with you, such as going for this procedure, so that you don't feel that you are unwanted in this world it gives the patient the motivation to carry on fighting.

UK Eng 11

The following quotation shows that the patient expected the wife to demonstrate emotional support, not least because of his help for her in the past:

Not acknowledging patient's support

Then she started the treatment and by the grace of Allah she is fine. Now during this period I had children and I spent my whole life on them now my wife said that I didn't do any thing for her, and that really makes me sad.

UK PK Post 5

We have categorised this as emotional support rather than tangible because she only expects her daughter to visit, rather than doing anything else more concrete, the latter would have construed this as tangible support.

My daughter once called me asking, how is your life going? We miss you so much. I told her that if you want to know come over and have a look.

UK Eng 11

Another aspect of negative emotional support is where patients believe that the priority being attached to their illness is less than it should warrant and that other family obligations are considered to be more important. Clearly this can be an issue where there are many family bonds.

...family priorities

they realized that I had a heart attack, they were more concerned about the marriage of my youngest sister, but I guess that is also important, it's very difficult to find good partner and she herself is in her mid thirties.

Post PK 1

I asked my children about their advice they all told me that it is my life and should be the one who should be deciding for it so all these things did not help me at all making me think that I should not go for a bypass.

UK Asian 3

This patient drew the link between provision of emotional support and the availability of time. This ties in with definitions of social support where people referred to emotional support as 'being there' for someone.

...lack of time

I built my whole family after my parents but now they have no time for me. So now I really felt the need of anyone who loves me, cares for me, waits for me at home. I mean to say I need a personal life.

PK PK 19

I am very thankful to her that she is coming all the way to see me. But I wish she could stay a bit more as she is only coming for 2 weeks and I know that it would be the last time we will be meeting.

UK Eng 19

Too much

In addition to others caring too little as being an example of no or negative social support, some respondents suggested that where others care too much, it can have a negative impact on them:

Yes I did get some support but the thing which happened along with that was that some 150 people came to see me there in hospital, thus the nurse came to tell me that it is an intensive care unit and I am having a lot of visitors.

UK PK 18

The other thing was that there was the nurses' counter just in front of my bed and there were frequent calls coming on their counter. I don't know from where my friends got the number from and they used to call me at the ward I told the nurses not to give any phone calls but I don't know what they used to say to the nurses that I have to go and talk to them. They were showing their love and affection for me to an extent that they would have got me killed because of it.

UK PK 18

She now mostly tries to stay at home rather going out with me. I guess that she is doing that as she does not want me to push her wheelchair but by doing that she is making me feel more guilty.

UK Eng 14

I wanted to rest but those phone calls did not allowed me to sleep or even rest during all that time. Due to the effect of medication I was feeling sleepy but I could not close my eyes the phone use to start at 8 in the morning and once I was receiving the last call at 11.30 in the night and none of the calls were shorter than half an hour. My relatives who were settled in US and in Canada called me for 2 hours at a time.

UK Asian 8

How care is delivered

We have looked at possible sources of negative social support being caring too much and caring too little. Here we see that where emotional support is provided, how it is provided can have an impact on the patient's perception of it. The following examples show how emotional care can be delivered in a way that it is perceived as being negative:

But the way they do that gives me an impression that they treat me as a child when my husband does that I don't mind at all, but when my children do this I really get quite upset.

UK Eng 15

Relatives generate fear

Yeah one of my relative said that it's a dangerous disease I don't know why but they want me to be in a state of fear. After that my wife start crying. Then I said don't behave like that not everyone dies because of heart disease, it depends upon Allah she don't know any thing.

PK PK 10

Due to not having information

I did not receive any emotional support from anyone. I guess it is not their fault, they don't know the seriousness of problem. I guess the main fault is with me as I have not told them about my problems but on the other hand they could have been more keen to know for themselves.

UK Eng 7

From nursing staff

Yes once I was going to have my first angiogram as I went in the operation room, the nurse asked me to remove my shoes and I removed my leg they all started laughing. Even the doctors it hurt me so much that I decided not to follow anything which they will say and that was why I did not follow you doctors until last time when I got admitted.

UK Eng 11

Impact of social / cultural issues

In these examples Pakistani respondents cite as a source of concern the behaviour of children. Specifically these concerns are related to the children not acting in accordance with cultural norms that the parents subscribe to:

I am waiting for my son to choose his bride only then there will be a marriage in which I will eat. And I won't mind high cholesterol diet just that once if you know what I mean.

UK PK 14

My son got married to an English woman and one of my daughters is living separately and now she also is marrying an Englishman, for the past year my youngest daughter has followed in the footsteps of her elder sisters and maybe we could also hear her news of marrying an English person.

UK PK Post 10

Difficulties in managing social conventions

Our Asians are always in lahaz and sharam (Urdu Words) I don't know if it's a good thing in us or a bad thing but it's there. We cannot say 'no' to anyone.

UK PK 18

13

INFORMATION SUPPORT



Introduction

Our coverage of information support deals with the following major categories:

- ❧ Sources of information
- ❧ Language and cultural problems that may hinder communication
- ❧ Shielding from information
- ❧ Information topics
- ❧ Information provision by the patient to others
- ❧ Patient perception of information
- ❧ Information support and emotional support
- ❧ Information support and tangible support
- ❧ Limitations of social support

Information source

The sources of information that people referred to were spouses, children, other relatives and friends.

Information quality depends on source

Given the fact that most of the information received by patients can be from friends and relatives who are not medically qualified, the problem of 'information quality' was raised by a number of patients. The following material shows what the issues are and there are also some ideas as to how patients try and deal with it:

It's because of they didn't know a lot they are not medically advanced. In Pakistan they constrict you - don't do this and that but in UK the doctor said eat everything but reduce oil in your diet instead of red meat use white meat and decreased the quantity of red meat vegetables and fruits.

UK PK 5

In starting it is **very difficult to tell everybody (in Pakistan) that these thing are prohibited to me by doctors. When we are invited** on dinner or in marriages people didn't realize that e.g. they say please don't be formal etc (but despite that it is difficult to say that some foods are restricted). But I must confess that it's all changing there now as well as now in Pakistan peoples get awareness from heart disease by TV programmes and newspapers

UK PK 12

He knows a doctor and he is spiritual as well. When I visit them with my sister, he said that I had no cardiac problem and I am only tense. I was shocked I told him that I had a heart attack and they give me 6000 rupee injection and you were saying that I have only tension?

PK PK17

Most of my friends are doctors they give me information.

UK PK 3

Such information can come from abroad:

My friend also helped me one of them is **doctor in Pakistan they called me & supported me that I should not worry & I should take this thing** & that thing once they have came to know my problem they are trying to help as they can.

UK PK 8

It should be noted that information quality may be compromised, because of relatives best intentions for the patient, as the quotation below shows, relatives may caution against bypass surgery because it may lead to pain for the patient:

In Pakistan relatives are very attached to you they love each other and **dont want you to get even a simple pain**, and the worst part is that they don't know that medically they are wrong.

UK PK 5

No they (people in Pakistan) don't, they don't want to harm you & they don't think bad from their side but its their habit to convey wrong information without trying it out first or even going into its detail. From their side think that they are telling you a good thing.

UK PK 13

I need good healthy food & he advised me that if I am not getting that food in my home, I can purchase it easily. I go to food market and eat what I want over there and eat less at home.

PK PK 17

Some of the respondents were quite frank about the quality of the information they receive from relatives being compromised due to the lack of education of those relatives:

But then my family in Pakistan is illiterate and my sons in London have only done few classes after that they all joined my business. It's very shameful that we are living in such an advance country but even then we are backward.

UK PK Int 17

No, yeah there is a train to make person in fear but it didn't happen with me because most of the person in my family are educated they give me positive influence.

PK PK 1

No he did not mention any time he just asked me to walk but then one of our relatives told me that it is good after your dinner as it digest all the food and avoid heart attack.

UK Asian 3

As well as information quality being compromised by relatives' lack of education, some patients also pointed out that the differences between orthodox western advice and that of relatives living in the Indian sub-continent, could be because of the differences in health services:

I didn't have much courage for the procedure and my children refused because of the fact that lot of cases in Pakistan of bypass surgery are unsuccessful. My brother died 7-8 years back during bypass surgery in cardiovascular hospital Karachi so they are very much afraid.

PK PK 4

I don't discuss any of my issues here in England to anyone there in Dhaka as they don't understand the thing which I am trying to tell them. They interpret what I say into some other meaning as they don't know the difficulties of living here in England. They just think in terms of things happening in Bangladesh and then they take a wrong impression out of nothing, so it is good to keep quiet than to give the wrong impression to others about your family.

UK Asian 5

The differences in quality between health services between the two regions may also mean that people from the sub-continent give more credence to alternative therapies:

No there is no difference they think in a same way I will go to Pakistan and be treated by 'hikmat' (traditional medicine) or go for tavez (religious charms) **I know a person in London he is my friend and getting treated by hikmat.** Even here my niece had a gall bladder stones and she don't want to go for surgery she want to be on (hikmat) medication. I said to her not to do this, go for surgery. They did go for surgery for that and when I saw the stones they were so big that it was impossible that they can be excreted through urine which according to them was their plan by using medication.

UK PK 5

We have previously seen the importance played by the spouse as a gatekeeper of information reaching the patient, this can be a problem where the spouse has a high regard for traditional remedies:

lot of times my friends do tell me follow different remedies but
I usually don't listen but my wife does follow them

UK PK 15

Quality - relatives may use sources of information the patient does not

My wife also tried her level best to pass on the usual
information to me, she used to watch different programmes on
television & then try to pass on the information to me.

UK PK 8

My husband reads newspapers, articles & provides me
information & I watch TV program related to heart disease

UK PK 10

He was with me all these years and we looked together at the
internet, he read different books and told me what to do and
what to not. One of my cousins gave me a book to read. Also
as no one knew anything in my family, everyone was keen to
know as they were very worried for me.

UK PK 7

I get awareness from the doctors and I go through some
websites of medicines and I gain a lot of knowledge from
there. Sometimes my son gives me leaflets and articles to read.
Yes I do pass on the information to others one of my friend
knows how to use a computer but the other one doesn't so I
give them the details in printed format
UK Post Pak 4

Spouse may be a conduit of information from others

The value of informational support from the patient's spouse (or children) is that they may have access to information that the patient does not. There can be a variety of factors behind this ranging from young people having a better knowledge of new media (such as the internet) to spouses in some situations being more sociable than the patient and having more frequent contact with a wider range of people:

Besides that my main source of knowledge is my wife. In these
past years she has developed quite a good source of
knowledge by talking to other patients and to other relatives
she is quite a popular figure in this area so she keeps on telling
me how to move ahead in my life and I follow her advice.

UK PK 15

My nephew instructed my wife & daughters about my food &
exercise, he said to them to avoid oily & salty diet & take oil
free, less salty, steamed or boiled food.

PK PK 13

My husband is always very against sending any news back to
India. He was also not in a favour of telling the news of my
heart attack but I asked my daughter to tell everyone as then
everybody could pray for me specially my mum she is 87 years
old and but the grace of God still doing well.

UK Asian 8

Note the above quotation needs to be moved elsewhere

Quality - Source of information may be cardiac patients themselves

Given the prevalence of heart disease and specifically its genetic characteristics, a number of respondents mentioned that friends and relatives could provide useful information based on their being cardiac patients themselves. This issue is raised again later when we consider the quality of information that patients receive, in that instance we will see that information received from other patients can vary in terms of its accuracy.

Most of the information given to me was by my relative who was himself a heart patient I think if he would not have been there, then I would have been very difficult for me to gather most of the information.

UK PK 8

My father-in-law used to have this problem for 15 years and I have gained a lot of awareness from him when he was alive, I know what problems he had to face and how he used to deal with them.

UK Eng 9

When the doctor comes or round he talks to his patient and rest of the patients in the ward listen and once he leaves we tend to discuss what he said. That way his point are made clearer, as usually all the doctors say the same thing, it's just a matter of time when they say it so some patients who are old have gone through that phase while the new one has to go through that phase.

When I was in a ward one of the patients who was in his fifties was asked by the doctor to be put on Warfarin. He got confused about what the doctor told him but even then he just could not understand what they were meaning by the term that they have to keep its level under some limit. I had been on that due to my abnormal heart rate before they put this pace maker in me so I went on to his bed and told him what doctor meant so the next time the doctor mentioned anything about that medication it made more sense to him.

UK Eng 10

Quality - People may pass on information from personal experience

The specific issue referred to here is the idea that patients may pass on information that is not just generically derived from other media, but is based on their personal experiences and for that reason appears to have special value for the patient receiving the information:

He tries to tell me different things, which he does for himself to keep himself fit

UK PK 14

Yes most of my relatives do give advice & I usually follow them. My friends are also keen to give me advice. One of my relatives told me some home remedies to help me cope with my condition. It was using onion juice along with garlic every morning before breakfast on an empty stomach. It opens your arteries & I think that was really worked miracles for me beside this there were other hikmat medicines that my relative sent me from Pakistan

UK PK 17

I made a lot of friends there and then you can say it was a place where we all used to meet and discuss what we have done during the week, such as how was our exercise going, on what medicine we are what are their reactions are on us and when you had heart attack what did you feel and how did you feel.

UK PK 18

In group exercise you tend to talk to others by doing this you share their thoughts, what happened to them so that you can analyze yourself, e.g. they tell us that after waking up you should drink 4 glass of water every day as by doing this your whole body system will clear and that you will feel good. Then someone asked me to do herbal treatment etc, so I think it's a good way of getting information.

UK PK 18

all of the participants in the walk are all heart patients thus they tend to know about their disease so they don't pass forward any wrong information

UK PK 18

Language & cultural problems hinder communication

Asian and indigenous patients communication problems

Some Asian patients mentioned their lack of language skills as inhibiting conversation with other indigenous English patients, however where the interviewees were based in areas where ethnic communities predominate this was not a problem:

They were giving information but only to other British friends, they were not talking to me. But some of the Asian patients were talking to me but they were even more illiterate and naive than me so they could not help me much

UK PK Post 1

Due to the fact that in this East Ham area there are a lot of Asians living here, you find quite a lot of Asian patients here whose English is not good due to the fact that they never went to any sort of school here in England. Most of us belong to a labour class which is not educated.

UK PK Post 1

But the second time I did make a lot of friends, especially in the ward. I was in there were others like me and the nice thing was that they were all women.

UK PK Post 2

As the last quotation highlights, for some Asian women where wards are segregated by sex, this may improve their ability to communicate with other patients.

Patient translates for others

Given the problem that some Asian patients face in terms of language, some patients mentioned having to translate for others:

I know one of the patients we occasionally meet he always call me whenever he is going to hospital. Once I went to hospital with him as his English is not that good thus he was unable to

understand most of the things which doctor used to tell him. Once I went with him I also got relevant information which helped me as well as him.

UK PK Post 1

This quotation highlights the value attached by some patients to finding someone else able to speak the same language:

On my fourth day of hospital I found 2 people they are talking in Urdu I asked them if they were Pakistanis as you tend to find lot of us Pakistani's here in East Ham. They said 'yes' then I joined them daily we used to talk for at least two hours in the courtyard in front of the cardiac ward. Before leaving hospital we exchanged our numbers so we can carry our friendship outside and the coincidence is that we are not living far from each other so after that we arranged a gathering once a week.

UK PK Post 4

Shielding from information

One of the features of information flows between cardiac patients and members of their social networks is the notion of the patient being 'shielded' from 'bad news', or at least having it broken in a gentle manner:

My sons try that I don't get any bad news just they form a shield for me against all the bad news

UK PK 1

There were reasons given as to why people may do this:

Not in the beginning but nowadays they do take caution. After my father's death I can't tolerate bad news when they told me suddenly about my father's death I start feeling chest pain & discomfort so now they behave like a shield for bad news.

UK PK 13

The shielding may be done gradually:

You cannot hide any news in today's world but yes they try to tell me gradually & if there is some news of death of any person who is in direct relation to me, my wife never gives me any such news. She first calls one of my relative & then tells me so that if anything untoward happens there is someone to take care of me beside her.

UK PK 9

But this can depend on the nature of the news:

They didn't hide anything from me, suddenly my sister died in India they told me immediately. I think these things depend on personal handling of the situation

UK PK 10

Finally, religious factors can be elicited in order to mitigate the impact of bad news:

My close relative died, at first they didn't tell me and when my son came from the office then they prepared me by saying that bad things always happen and every body has to return back to Allah and then told me.

PK PK 3

As well as external news being shielded from the patient, some relatives may also try and shield the relative from information about their own health, however the patients themselves may not always appreciate this:

They (relatives) were not talking to me they were coming and asking how I am but I must tell you here that I wanted to talk to them as I was worried but they were just ignoring me they think that you should not discuss anything in front of patient. I think they were very silly and stupid, either they are or the doctor was you can decide yourself. My doctor was telling me everything, he did not hide anything from me and my relatives were trying to hide - what do they think am I a stupid person?

UK PK 11

Information topic

Here we deal with the different substantive topics that are covered by 'information support'.

Routine material

Yes sometime my relative have a chat about my health they ask how I am feeling and the other routine things.

UK PK 20

Music

Yes I do go to sleep early, drinking excessive water, listening to light music specially the sounds of rain and waves it really helps. One of my friend gave me the music of rain forest and it really helped.

UK PK 18

Diet

Yes my elder sister who also had a heart attack just before mine she advised me to use low oil in food & decreased salt in diet & avoid doing hard work.

PK PK 4

Medicine & treatment

Yes my relative is also a smoker once he was prescribed ACEI medication which has a side effect of coughing but he did not know about that. He thought that the cough he was having was because of smoking, this carried on for a month until he discussed that issue with me. The first question I asked him was if he was on Capoten. He told me that he was on that so I asked him to see his GP and ask him to change, which he did and after that his cough was gone.

UK Eng 12

The nurses at the nursing home are very careless as they know that is there is no check on them. I thought that I shall tell the others about it as there were some patients there who were not in their senses they won't know what would be given to them. After that I told all the patients to look before they ingest any medications and have a look at their neighbour's tablet if he can't do that himself. By doing that I made sure that everyone got the right tablets. Since then all those patients became my friends and once I got discharged from there I used to go and see them on every Saturday evening.

UK Eng 13

Yes I give advice related to food about butter and meat and also for walking. Walking is very necessary for our health.

Once one of them told me about the sublingual tablet that if I am not comfortable with that spray I can use that in a tablet form as well.

UK PK Post 6

I was admitted for my bypass. We were operated on same day by the same surgeon, so our routines were the same he was also from Liverpool and it was good getting along with him as he was having the same problems which I was having. So we tend to know what we are going through, then we were having quite the same problem. He himself did not know about the disease until it arrived and it was a good experience knowing a local Englishman from that close. We have became very good friends, since the time my wife brought two bouquets, one for me and one for him on the fourth day of our operation it was quite nice.

UK Asian 6

But then he told me that those are the normal things associated with that medicine as he was also using that, it had a very calming effect on me.

UK Asian 8

Experience of having heart attack

Because among our friends we discuss our problems and there once it was in a discussion as one of my friends got a heart attack. She then told everyone else after getting discharged from the hospital about how it happened and what did the doctor tell her to do. After that she told us how she could have saved herself from much disaster if she would have known that I had a heart attack. In her case she was getting this pain for more then 8 hours and she was taking painkillers and sedatives, so once they diagnosed her as having a heart attack according to the doctor it was too late, by then, for some medications to be given which could have limited the destruction of the heart.

UK Eng 20

We did share our symptoms. He was admitted there with the heart attack just as I was, but it was his second heart attack in one year. He was curious to know that why did the heart attack happen so quickly but I think he was a very care free person and that was the main reason of his heart attack

UK PK Post 8

Cardiac rehabilitation

There were lots of problems firstly there is a parking problem so I recommended them not to come in their cars and take a lift instead, that way they could avoid a lot of trouble. Then I recommended for their comfort and safety to wear loose fitting and comfortable casual clothing. Ideally soft footwear or trainers are most suited while exercising on that equipment. Beside that as a courtesy I told whoever asked me to go there, having a small hand towel for their personal use. And all of them were always very happy to take this advice of mine that saved them from lots of undue trouble.

UK Eng 20

General UK lifestyle issues

I gained lot of knowledge from that rehabilitation group the knowledge I gained from my hospital friends was more regarding my rights as a citizen of England, which really

helped me coping with my life at home I think every elderly person should know their rights.

UK PK Post 2

Social services

I have these friends, they keep on telling me if there is some walk going to happen or any new nursing program. They told me about this dial-a-ride concept and that has eased my life a bit as I cannot drive anymore. And then they told me about these cholesterol lowering tablets, I was not sure about the timing so I mailed one of them and the told me that I should have it before going to bed rather than just after dinner etc.

PK Post 5

Information provision by the patient to others

I don't discourage them to take allopathic medication but I also tell them to do these home remedies, after all what is the harm in having onion and garlic juice every morning if you can tolerate it?

UK PK 17

Questions asked by relatives

Gohar always asks me that if I am so strict with my food how come I am not losing my weight?

UK PK 3

In order to elicit social support

The thing which went wrong is that once you have some problem my friends use to hide that from everyone. But I asked my friends to tell everyone that I had the heart attack so they could pray for me as it was the month of Holy Ramadan.

UK PK 18

Information provision can overcome fear

Yes, I provide the literature and verbally told them. My neighbour, he was very afraid of a bypass. I told him and tried to guide him, that look I am perfectly fine and doing my all work properly like driving etc. just as I was before my bypass and I am not facing any difficulty. Then he decided to have bypass surgery. I also advised many people related to the cardiac disease.

PK PK 1

Yes, he did but that patient told me from the perspective of a patient and not the doctors'. Believe me that his words helped me more than what doctor did tell me. As a doctor you don't know what things worry the patient only a patient can address all those concerns.

UK PK Post 10

Based on own attitude to health

No I didn't, if somebody said we are diabetic & sweet things are prohibited by the doctor then I said eat a little it won't affect your health. I advise eat each & every thing, don't do perhaiz. Allah will help you. I said Ya Ali Madad (religious invocation) & climb the stairs & I am fine, it's my faith nothing bad happens to me.

PK PK 8

Can help the patient feel good

I am talking to one relative who is very frank with me, he used to discuss his cardiac problems with me as according to him I am the senior in this disease and I know quite a lot of things more than him. It feels good when you help someone.

UK Eng 12

Yes, he did but that patient told me from the perspective of a patient and not the doctors. Believe me that his words helped me more than what doctor did tell me. As a doctor you don't know what things worry the patient more only a patient can address all those concerns.

UK PK Post 10

Patient perception of information

Information provision can be subtle

I have 4 persons in my family who are doctor two sons and two nephews, they do give me lot of advice but they don't force it on me.

UK PK 16

Patient can become irritated

Yes, but its boring. I don't want to hear about it any more. First my doctor then my family then my friends they provide me all information verbally one of my friend bring leaflets of AKU for me, even on T.V my family is trying to look for new researches on my disease. It's annoying now.

PK PK 10

Limitations of social support

I think it is not the information which is important it is the implementation of the information for example you can get information from doctors from nurses from books from computer but the difficult part is following them for me my religion has solved most of that problem for me.

UK Asian

14

LINKS BETWEEN INFORMATION, EMOTIONAL & TANGIBLE SUPPORT



Introduction

Although it had not been part of the original research agenda, it quickly became clear that respondents were making links between the different types of support. Specifically they were linking emotional support with the two other types of support, tangible and information. We have brought these links together within one section, to enable a clearer exploration of the linkages that have been drawn and any possible implications from these relationships.

Emotional support and tangible support

Some respondents drew explicit links between the tangible support they received and the emotional support that they associated with it.

I made sure that I go to play golf every day that is way I made new friends as well as keeping my exercise going

UK Eng 12

At that time my husband was alive and use to take care of me he was a very nice man while he was alive he supported me as much as he could, I was very lucky to have such a person as my partner. We never used to fight but after his death I totally crumbled I was very close to him and then there was no coming back, my health went into a steep decline until this day.

UK Eng 19

Yes my son and his wife have changed their lifestyle for me but not because that they love me but because of Rosemary's advice. Now they don't watch television till late at night. Neither do they come home really late as then I don't open the door of my room.

UK PK Post 2

Contrast tangible support and emotional

Two years back I called my elder son telling him that I want to have my bathroom done as it very hard for me to manage now, after this heart attack, in my old bathroom. So he came with some labour, he is in a construction business and fixed my bathroom. I tried to come close to him by asking him that he should eat something its his house but he did not even drink water at my place.

UK Eng 2

I am telling to tell you here that it not only physical support which is important, you can get physical help even from caretakers but the main support which the caretakers can't give you is emotional help because for that you have to be emotionally attached to that person, the emotional support is all about thinking for others.

UK Eng 6

Others changing lifestyles and impact on emotional support

One of the ways in which people said emotional support was received was when others changed their own lifestyles in order to help the patient:

Giving up smoking

My son-in-law who lives in Chester was a smoker but once he came to visit me in hospital and saw that I had a heart attack and how serious it could have been if I could not have got treatment in time (even with the type of life I am used to living e.g that I don't smoke I don't drink and I go walking), he then analyzed his chance of getting a heart attack and finally decided to quit smoking. And it really made me proud.

UK Eng 9

Yes they do and it has a positive effect on others I give you an example that when my wife told my warden in the sheltered accommodation about my disease she stopped smoking and I guess it's good if you can be a positive inspiration for others.

UK Eng 9

They did not take this problem as seriously as me. They continue to practice the same lifestyle as before. One of them is still a chain smoker and other one is too busy in earning money that he has no time for himself he does not realize that all this money will be useless after our death.

UK Asian 7

No one changes in this world for you they are all same. The difference is that now they have started to keep in touch with me a bit more, besides that every thing is the same house, job, life, problems.

UK Eng 17

Emotional support and information support

My wife is very fond of calling our relatives in Pakistan they gave her tips on how to improve my health. Someone tells her some verses from Quran. The calling card system has really worked for us.

UK PK Int 17

Informed relatives can display emotional support

First we decided not to tell them as we thought that they will get upset but then I decided to tell them that I had a heart attack. Once they come to see me on that day they didn't know that I had a heart attack, their response was different. Once they were told by my sister that I had a heart attack that day, when they came to see me the response was totally different.

UK Eng 1

Emotional support may be preferred to informational support

When they give me advice I listen to it from one ear and let it go from other, they just give advice as a formality. If they really want to help me they can come and stay with me at my home for some days and see what I need in my life, it's not advice what I need I need genuine input in my life.

UK Eng 11

Information support does not need to involve friendship etc

I have met a lot of good doctors and patients during my stay here and they have been my friends as well, but the friendship finishes here in the hospital. Once they get discharged from hospital or I got discharged, the way they keep in touch with me is through internet. I sometimes mail them and one or two of them usually respond, it's good to know about them every now and then.

UK PK Post 5

I do tend to talk to all the other patients in the ward but none of them was my friend.

UK Asian 4

Can lead to friendship

I told you that I am very social so I make friends in hospital and share their problems and I even continue my friendship outside the hospital and we are friends now, if any one of them needs me I always ready to help them.

UK PK Post 6

Confused with friendship

Actually I am very reserved person. Also I don't like to talk much and in hospital I don't like to talk at all. It's all very tense once you are there in hospital and I was there only for a week how can you make friends in such a short time?

UK PK Post 7

Receipt of information can provide social support/company

Yes one of them did give me advice. He was a very nice gentleman availing every opportunity to talk and give his views and I guess I was the only person in the ward who was willing to listen to him for hours. As it was his second heart attack, he was much more aware than me. He told me to avoid red meat and eat chicken and fish and use decreased salt and oil in food, he was a very strict follower as far as advice for foods was concerned.

UK PK Post 10

We talked about the daily news, if someone is very depressed we sometimes specially go to have a word with him. If someone is going for some test we talk to him, if he is very worried it really helps.

UK Asian 2

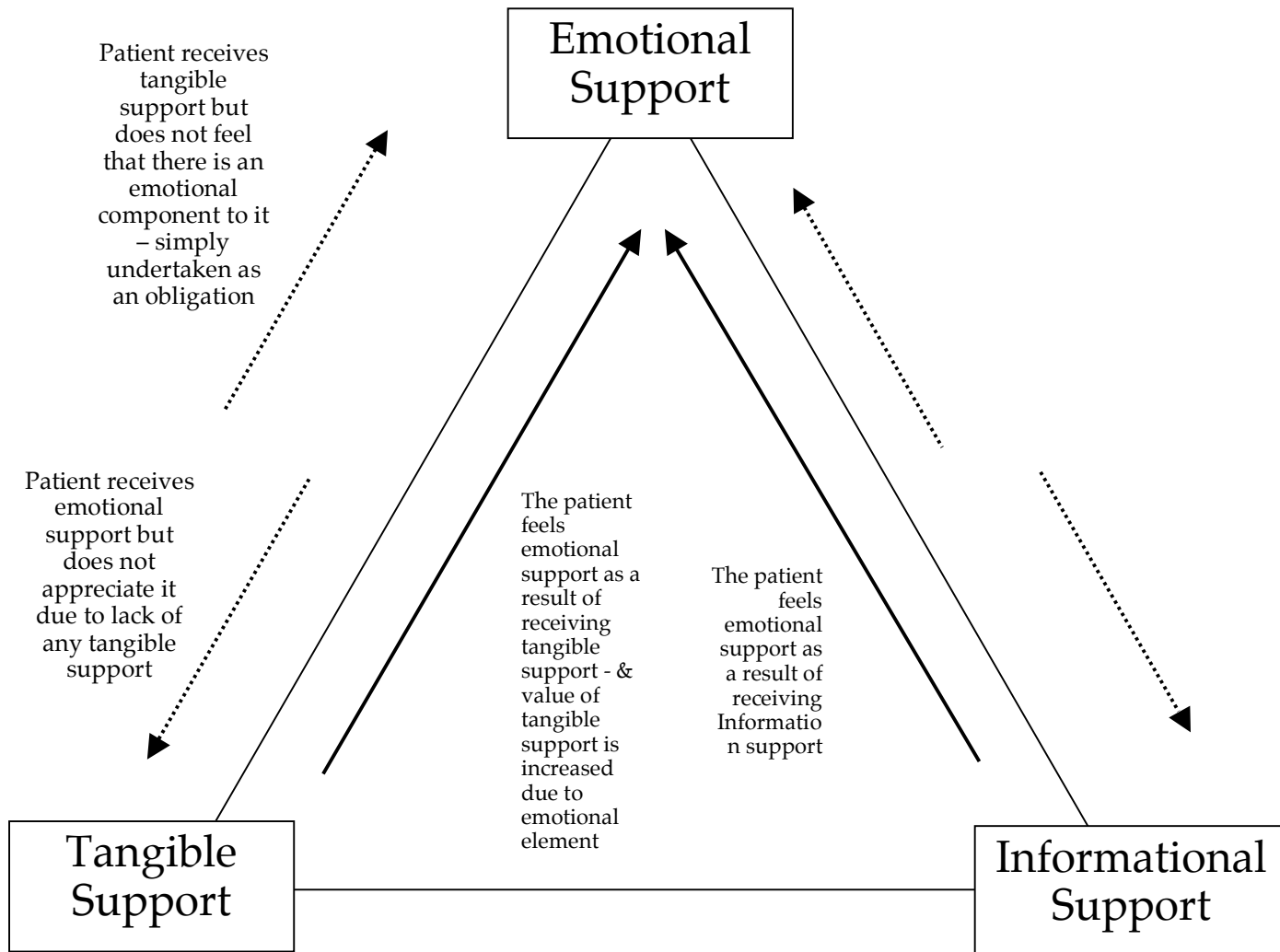
Information support and tangible support

My youngest daughter said she is doing medicine but she didn't force me. She also prohibited me from red meat, sweet dishes and oily food and always said take medicine on time. If I don't want to go for routine check up then my daughters and my sons forced me and my little daughter take appointment by herself.

PK PK 4

Yes, I tried to follow or I can say that I was made to follow doctor's advice by my wife, as she was the one involved with the cooking. Since then she started to give me more & more vegetables & less meat. She then asked one of our relative who was a heart patient about the type of oil & the type of food they eat.

UK PK 8



15

COMPARISONS BETWEEN DIFFERENT GROUPS



Introduction

In this section we will explore the differences between the different groups of respondents. As was explained earlier in this report the main cohort of respondents was British-Pakistani and the other cohorts were used in order to highlight any issues specific to that group of people.

Comparisons with indigenous Britons

The following were identified as key differences between the main cohort and the indigenous British group of respondents:

- ❧ It should be noted that on average the indigenous Britons were older than the main cohort. This reflects the profile of heart disease patients in the UK, where South Asians are more likely to suffer at a younger age
- ❧ The indigenous British group almost universally was taken to hospital by ambulance – this compared to the main cohort who were predominantly taken by relatives

- ❧ There were clear differences in issues of proximity between the two groups. The indigenous Britons were far more likely to talk about children living far away.
- ❧ Indigenous Britons were much more likely to talk about usage of social services such as care homes.
- ❧ Indigenous Britons were much less likely to talk about the involvement of people other than spouses and children. For some it even seemed to be an issue whether or not they told other people about their condition.
- ❧ Indigenous Britons also talked much more about making friends and exchanging information with other patients in hospital. Where the main cohort did raise this issue they commented that lack of language skills often held them back
- ❧ Indigenous Britons did not talk at all about any social norms or conventions that made it a problem for them to adhere to a healthy lifestyle. Some spouses of smokers did say that their partner's refusal to give up smoking made it very hard for them to do so. No South Asian patients made this comment.
- ❧ Indigenous Britons were more likely to refer to a range of cardiovascular exercise (e.g. swimming and going to the gym) than the South Asian respondents for whom walking was likely to be the only form of exercise.

Comparisons with Pakistan based respondents

The following were identified as key differences between the main cohort and the respondents based in Pakistan:

- ❧ The Pakistani-based respondents were much more likely to refer to the use of traditional medicines to deal with coronary disease. However there were some in the main cohort who had tried these on trips to Pakistan
- ❧ Pakistani based respondents were much more likely to refer to religious invocations when referring to their heart disease, than the main cohort.
- ❧ Problems associated with the social management of heart disease were more likely to be referred to by the Pakistani respondents. Such problems included going to relatives who would not serve healthier food to them. This could be due to people there having a wider circle of friends and relatives than is the case here.

Comparisons with other Asians

There were no obvious differences between the main cohort and other Asian groups.

15

SOCIAL MARKETING MATERIALS GENERATED BY THIS RESEARCH



Introduction

In this section we look at some sample materials that have been generated as a result of this research and which could be used to disseminate the findings to a wider audience.

The specific materials are a press release aimed at Asian media, the second is a case study that could be used as part of a public relations campaign, but it could also be used in other contexts.

Press release

‘Just one samosa won’t hurt’. ‘Please help yourself to this onion bhaji – I’ve made it fresh’. This is likely to be a phrases that all people who suffer from heart disease have heard at one time or another. For people from India, Pakistan and Bangladesh coping with life after a heart attack, coronary bypass or angioplasty can be difficult, not least because of the lack of understanding shown by friends and relatives.

A study undertaken by the Open University’s Institute of Social Marketing and Whipps Cross University Hospital has found that although for South Asians family and friends can be a great source of help and encouragement, these people can create problems as well.

Dr. Haider Ali who undertook the study, with funding from the British Heart Foundation says, 'there is a lot of ignorance and misconception in the community and patients can find it hard to live a healthy lifestyle'.

In particular where patients have relatives in the sub-continent they can be encouraged to try traditional medicines as an alternative to modern treatments. We've had some patients whose relatives advised traditional medicines as an alternative to bypass surgery, this can be particularly problematic where the patient is scared of such surgery and would like an excuse to put it off.

On the positive side the study has found that families can work together to help cardiac patients lead healthier lifestyles. 'We found some patients whose families made no change to the food on the dining table, but at the other end of the spectrum were families that changed the diet for everyone in the household so that everyone could benefit from a low fat and low salt diet', says Haider Ali. The study also found that some families undertook exercise and other daily household chores together and this type of support can be a useful way of reducing stress.

Perhaps surprisingly the research has also found that when someone has a cardiac event such as a heart attack, or a bypass the event can be the motivator for an improvement in relations between family members. People who may not have been on speaking terms realise that life is too short and patch things up.

Of course not all South Asians have access to friends and family and the report also found that heart disease can be a catalyst for Asian patients to talk to people and make friends outside their immediate communities. We found that some people were willing to talk to other patients in their wards and in cardiac rehabilitation classes and for some although no friendships came out of this they were able to get a lot of useful information from other patients who also had heart disease. For others the people they met at hospital subsequently became exercise buddies.

Case Study

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